

**The experiences of people living with HIV and AIDS receiving health care services  
at Lighthouse clinic, Lilongwe-Malawi**

**“A contribution to an understanding of the basis of HIV and AIDS related stigma in Malawi.”**



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## **Abstract**

It is widely recognized that HIV and AIDS related stigma is a hindrance to provision of care and prevention efforts globally. Malawi being one of the countries with a high HIV prevalence rate in the sub-Saharan region has not been spared of this epidemic and the challenges that are brought by stigma. While a number of surveys have indicated the magnitude of HIV and AIDS stigma little is known on how HIV and AIDS stigma is constructed in the Malawian urban setting.

The purpose of this study was to explore the experiences of people living with HIV and AIDS in Malawi where stigma attached to HIV/AIDS has been reported to be a big challenge.

This was an ethnographic study that was conducted in a clinic setting in an urban area of Lilongwe in Malawi. Data was generated through 25 and 11 semi-structured interviews with people living with HIV and AIDS and with people holding key positions in HIV and AIDS related activities.

The findings demonstrate interplay of a number of socio-cultural factors that underlie the construction of stigma in Malawi and how it has affected PLWHAs lives at different societal levels. The cultural factors have influenced the way people attach meanings to HIV and AIDS as well as to the people infected.

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## **List of acronyms**

HIV	Human Immune deficiency virus
AIDS	Acquired Immune deficiency syndrome
NAC	National AIDS Commission
PMTCT	Prevention of Mother to Child Transmission
MDHS	Malawi Demographic Health Survey
MDG	Millennium Development Goals
PLWHA	People Living with HIV and AIDS
LCH	Lilongwe Central Hospital
VCT	Voluntary Counselling and Testing
ARV	Antiretroviral therapy
IEC	Information Education and Communication
NORAD	Norwegian Agency for Development Cooperation



## **Section: A**

### **Chapter 1:0 INTRODUCTION AND BACK GROUND INFORMATION**

#### **1.1 Introduction**

HIV and AIDS remains the major public health challenge globally. The joint United Nations Program on HIV and AIDS (UNAIDS) and World Health Organization (WHO) estimated 37.8 million people living with the virus world wide in 2004(1). Out of this, 2/3 was reported to be in the sub Saharan Africa. Malawi being one of the countries in this region with HIV prevalence rate of 14.2% in the adult population(15-49 years) has not been spared of this epidemic(2).

Since the beginning of HIV and AIDS epidemic, stigma attached to it has been widely recognized as a significant hindrance to the provision of care and preventive efforts. In Malawi surveys have indicated the magnitude of this problem however, little is known on how stigma is constructed. This study therefore, is an effort to contribute to an understanding of how HIV and AIDS related stigma is constructed in Lilongwe, an urban setting in Malawi.

The need to study this topic came following a number of encounters with people living with HIV in counselling sessions at one of the clinics in Malawi. This was a period between May 2002 and December 2003. Some of these clients complained about different challenges that they had encountered because of their HIV status. Their narration indicated that HIV and AIDS diagnosis caused a lot of social suffering in the individuals infected. Some women complained about having lost their marriages because of HIV diagnosis. It is therefore in this regard that I thought of exploring the depth of the experiences of living with HIV and AIDS.

## 1.2 Malawi Country Profile



### 1.2.1 Geography

Malawi is a land locked country situated in the southern part of equator in the sub-Saharan Africa. It shares borders with Tanzania in the north and northeast, Zambia to the north and northwest and Mozambique to the east, south and south west as indicated by the map above. It covers a total land area of 118,484 square kilometers. Of which 94,276 square kilometers is land and 475 kilometers is filled with water. The width of the country ranges from 80 to 161 kilometers and it is 901 kilometers long. It has tropical climate, rainfall season starts in November to April. Temperature and rainfall vary from place to place depending on altitude and distance to Lake Malawi(2).

The country is divided into three regions: Northern, Central and Southern region. These regions are divided into 28 districts; six districts in the North, 9 at the central and 13 in the southern region. The districts are subdivided into Traditional Authorities that are headed by Chiefs. These Traditional Authorities are further divided into villages which are headed by village headmen/women (2).

### **1.2.2 Economy**

Malawi is one of the least developed countries in the world with a Gross Domestic Product (GDP) per capita of US\$ 195.3(3). It is one of the countries that were approved for debt relief under Heavily Indebted Poor Countries Program in December 2000(4). Rain fed agriculture is the backbone of Malawi's economy which accounted for about 35% GDP, employing about 84.5% of the labour force and brought about 82.5% of export revenues in 2002. The major export crops are tobacco, tea and sugar. The dependency of Malawi's economy on the rain fed agriculture, has made the country's situation vulnerable in cases when there is drought and/or fluctuation on the World market(2). This has affected the livelihood of most Malawians. The country relies heavily on the substantial inflow assistance from the donor community, International Monetary Fund (IMF) and World Bank (WB) to supplement its meagre resources (ibid). HIV and AIDS has been reported to undermine the country's efforts to reduce poverty hence about 65.3% of Malawi's population is living below poverty line(3).

### **1.2.3 Population and demographic information**

Malawi had an estimated population of 10.5 million people with an annual population growth rate of 3.1% in 1998. The total fertility rate is estimated at 6.2 per woman of child bearing age due to early child bearing and a low contraceptive prevalence rate(2).

Life expectancy at birth was reported to have dropped from 43 years 1996 to 39 years in the year 2000. This decline was related to HIV and AIDS epidemic(5). In the year 2000, infant and under five mortality rate was estimated at 104 and 189 respectively per 1000 live births while maternal mortality was 1120 per 100,000 live births which has been attributed to limited access to health care services(3).

Malawi has a socially diverse culture, it consists of people of various ethnic groups. That includes; Chewa, Nyanja, Tumbuka, Yao, Lomwe, Sena, Tonga, Ngoni, Ngonde. The population consists of people from different religious beliefs. Most of the Malawians are Christians followed by Muslims and some minor groups are affiliated to traditional beliefs(2).

### **1.3 Overview of HIV and AIDS epidemic in Malawi**

Malawi is one of the countries in the sub-Saharan region that has high prevalence rate which is estimated at 14.2% in the adult population (15-49 years)(6). With high prevalence among urban adult population estimated at 25% while rural is estimated at 13%(7). The prevalence rate for women and girls is estimated at 57% of the HIV positive adults' population(8). National AIDS commission report (2003) has shown that there are more young women living with the virus than men of the same age(9).

The first HIV and AIDS cases in Malawi were identified in 1985. Since then the epidemic has taken a great toll on the productive age group (15-49) of the population of Malawi. Such that it has brought challenges to the country's efforts to fight the epidemic as well as the country's efforts to reduce poverty thereby increasing food insecurity and threatening the community survival(10). Estimates have shown that over 700,000 adults and children have since died of HIV and AIDS related illness between 1985 and 2004(2).

The epidemic has created a devastating impact on the country's resources such that labour is diverted from productive activities to care provision. Country estimates have shown that about 900,000 adult and children were living with HIV and AIDS at the end of the year 2003(6).

In Malawi, HIV is predominantly transmitted through heterosexual sex, followed by mother to child transmission. Transmission through infected blood and sharps such as needles has been reported to be less than a few cases(9).

#### **1.3.1 National Response to HIV and AIDS Epidemic**

Malawi's response to the epidemic started in 1986. The response was more of medical oriented approach that included; blood safety, public awareness and training of health care providers. Mainly the goal was on prevention of further spread of the HIV infection(11). A medium term plan followed from 1989-1993 which underpinned multi-sectoral approaches (involvement of different stakeholders) and incorporated the other dimensions on the impact of the epidemic such as social and economic.

The government in 1996 evaluated the extent of the impact to which HIV and AIDS Control Program activities had on the Malawian community. The evaluation process established that despite the 90% awareness level behaviour change was a big problem and HIV incidence cases were on the increase(12).

Later the National AIDS Control program and other stakeholders formulated the National HIV and AIDS Strategic Framework for the period from 2000-2004. The aims were as follows: a) to reduce incidence of HIV and other sexually transmitted infections, b) improve the quality of life of the people infected and the affected and c) mitigate the impact of HIV and AIDS in all sectors and all levels of Malawian Society. The framework emphasized on need to expand on multi-sectoral approach to the fight against the epidemic(11). In the year 2001, Malawi at the Abuja and United Nations General Assembly Special Session Declaration (UNGASS) of commitment in the fight against AIDS committed itself to the development and implementation of multi-sectoral national strategies in the fight against the epidemic.

In May 2000, Malawi started development of a new HIV policy document which was later launched in 2004. The policy's objective was to guide national response to the epidemic to mitigate impact of HIV and AIDS and stop HIV transmission. In 2001, the government established the National AIDS Commission to coordinate and provide leadership to all HIV and AIDS activities in Malawi(4).

In recent years, interventions such as Prevention of Mother to Child Transmission (PMCTC), Voluntary Counselling and Testing (VCT), and syndromic management of sexually Transmitted infections (STI) have been central in the fight against the epidemic. Focus from primary prevention that focused on behaviour change expanded to bio-medical interventions, care and support(11). In 2003, the program focus was streamlined into seven program pillars to operationalize the National strategic framework and to facilitate monitoring and evaluation with the health sector as a key player in some of the areas. The seven pillars were as follows;

- 1) **Prevention and advocacy**, this program covers wide range of activities and services aimed at behaviour change and prevention of transmission. The activities among others include: behaviour change and communication interventions, promotion of safer sex, VCT and PMTCT programs.

- 2) **Sectoral mainstreaming**, this program area was to enable public institutions, private companies and civil society organization to mainstream HIV and AIDS in their work place and businesses to mitigate the epidemic's impact on labour productivity and service delivery. This involved participation of people living with HIV and AIDS.
- 3) **Treatment care and support**, this program covers a range of health based interventions aimed at reducing the morbidity and mortality associated with HIV and AIDS. This category was divided into two; clinical care and home based care programs.
- 4) **Impact mitigation**, this program aimed at mitigating the impact on vulnerable members of the society such as orphans and others.
- 5) **Capacity building and partnership**, this is a program that aimed at building the capacity of stakeholders to implement the multi-sectoral response to the epidemic
- 6) **Monitoring and evaluation**, this involves collection and analysis of data in order to monitor, evaluate and adapt its interventions. Health sector is the key player.
- 7) **National leadership and coordination**, this involves national leaderships by Ministry of health and the National AIDS Commission in the implementation and monitoring of HIV and AIDS programs(11).

To run these programs Malawi Government applied for monetary support from the global fund. At the end of the year 2002 the country received final approval of US\$ 196 million over five years but it took some time before the funding was disbursed to Malawi government(4). In 2004 with the aid from the global fund the country expanded its programs and started providing free ARVs and other HIV primary health care services for HIV infected persons in all the country's district hospitals.

The NAC summary report on evaluation of the year 2004 indicated some achievements that the country has realized through the Global fund on the targeted programs. Among other achievements the report indicated that; there were 128 sites offering counselling and testing at the end of the year 2004 as compared to 118 sites in 2003, over 32,000 PLWHAs were on ARV treatment as of November 2005 from less than 5,000 in early 2004. About 61% of the public sector ministries and 47% of large companies reported to have developed HIV and AIDS work policies and programs.

The report also indicated greater involvement of public institutions such as interfaith organization in the activities to help mitigate the impact of the epidemic(13).

The government has emphasized on the multi-sectoral approach (collaboration among public, private and civil organizations) in the fight against the epidemic with NAC as a co-ordinating body for all HIV and AIDS related activities in Malawi. The government realized a need to adopt “three ones” global principles in the fight that includes; 1) One agreed AIDS action framework, 2) one national co-ordinating authority and 3) one agreed country level monitoring and evaluation system. NAC reports all its duties to the Office of the President and Cabinet.

It is worth noting that by the end of December (2005) Malawi did not have specific laws and regulations that protect the rights and dignity of HIV infected and affected individuals(14).

### **1.3.2 HIV and AIDS related stigma in Malawi**

Malawi like other countries that have been affected by HIV and AIDS in the sub-Saharan region has also reported of the challenges that stigma puts across care and prevention efforts. Garbus (2003) indicated that stigma was one of the limiting factors to the country’s efforts to fight against the epidemic(4). A baseline study that was conducted to examine community beliefs, attitudes and behaviours related to HIV and AIDS from eight districts in Malawi indicated a number of factors that were identified as the basis of stigma in Malawi. That includes: the association of HIV and promiscuous sexual behaviours, lack of self control of one’s sexual impulses, beliefs that HIV infection is a punishment from God because of disobedience to parents and God(15). A qualitative study that examined stigma with an aim of informing the development of HIV and AIDS Malawi policy document (2003) indicated that stigma is a challenge to care seeking behaviour, and create loss of employment and other life opportunities in the individuals infected(16). Malawi demographic health survey 2000 (MDHS) and the Malawi behavioural surveillance survey (MBSS) indicated that people do not have accepting attitudes towards people living with HIV/AIDS(2;17). The MBSS attributes this to misconceptions about how the disease is transmitted. Despite decades that have passed since the first cases were identified and all the efforts to stop the epidemic National AIDS Commission in its annual

monitoring and evaluation report for 2004 indicated that stigma is still a challenge to the county's efforts and People living with HIV and AIDS (18).

It is worth noting that in Malawi the literal translation of stigma does not carry the same meaning of stigma as it has been defined by the theoretical framework that guided the investigation of stigma in this study. Stigma in the Malawian urban setting of Lilongwe means "isolation." It is in most cases used interchangeably with the term discrimination. This was captured in public health teachings, health education session at the clinic and radio advertisements that encourages acceptance of people living with HIV and AIDS.



### **1.3 Thesis structure**

This thesis has been divided into four sections that consist of eight chapters. Section A, which is the first chapter consists of the introduction, Malawi country profile as presented in the previous pages. The remaining parts of this chapter discuss about the gaps identified from the literature review that was conducted to inform the development of research protocol. Objectives of the study have been indicated followed by justification of the study and the theoretical framework that guided the exploration and interpretation of the study findings.

Section B, which is chapter two, discusses the methodology that was used. That includes: description of the study setting and reasons for the choice of this setting, methods for data generation and reasons for the choice of the methods, description of the study sample and justification of the selected sample.

Section C, which is third chapter, I have attempted to discuss the social and institutional structures that helped with the interpretation of the experiences that participants shared in this study. These structures include; Malawian family structure and social relationships, gender relations and roles, religion and religious institutions, and sex and sexuality issues.

Section D of this thesis discusses the findings that have been presented in 4 themes. The themes have been presented as 4 separate chapters. That includes; HIV and culture, the consequences of living with HIV, management of reputation in the community and the beginning of new life. Before the presentation of the themes a description of the clinic setting and HIV testing process has been given highlighting on how the environment impacts on the lives of people receiving counselling and testing.

At the end of the findings chapter I have attempted to give a conclusion of the study findings and pointing to areas that need more focus to help reduce stigma and improve the lives of the people living with HIV and AIDS.

#### **1.4 Current knowledge on HIV and AIDS related stigma**

The first part of this thesis was a literature review on HIV and AIDS related stigma. The literature review covered the global perspective of stigma, forms and contexts of stigma, causes of stigma in different contexts as it is widely accepted that stigma has its basis in the cultural embedded meanings that centres on deviance. Learning from the previous HIV and AIDS related stigma studies from other contexts as well as literature from Malawi gave an overview of the field in which work was to be done. Presented below are the gaps that were identified from the reviewed literature.

##### **1.4.1 Research gaps and objectives**

Literature reviewed indicated that research response on HIV/AIDS related stigma in Malawi has been limited. Surveys and studies that were conducted in this area focussed on public attitudes towards HIV and AIDS and the people infected. Not much has been done on how stigma is constructed, factors that influence stigma and how people being stigmatized cope with it socially. The MDHS (2000) indicated that stigma is more prevalent in the rural areas. Therefore, it was imperative that a study exploring the experience of the people living with HIV and AIDS conducted in the urban setting to find out if stigma exists. If it exists find out how it is constructed. A study proposal was developed with an aim of exploring the experiences of people living with HIV and AIDS in Malawi where stigma attached to HIV was reported to be a challenge. The following objectives were formulated to help achieve the main goal; to explore the meaning of stigma in Malawian urban setting, to investigate on how stigma is expressed in different interpersonal relationships and institutional settings, to explore how the stages of disease development influence the way in which stigma is expressed and finally to explore how the stigmatized respond and cope with it.

##### **1.4.2 Research questions**

The following were the research questions that guided the exploration of the phenomenon.

1. Are people with HIV/AIDS being stigmatized in Malawi? If so how is this expressed in practice?  
And in which situation?
2. How do people with HIV/AIDS react socially to their situation (being HIV positive)?
3. How are they coping with the social response to their diagnosis?
4. Are people with HIV and AIDS accessing institutional services such as health, social and spiritual

care?

5. How do they perceive care and support from their families and friends?
6. How do they view changes in their lives brought about by their diagnosis?

#### **1.4.3 Justification of the study**

Malawi through the Abuja declaration and United Nations General Assembly special session declaration of Commitment on HIV and AIDS in 2001 and the Millennium Development Goals (MDG) made a commitment to fight HIV and AIDS. Among other things the agreement included: confronting stigma, silence and denial, eliminate discrimination and marginalization, fully promote and protect all human rights and rights to attain standard of physical and mental health and to reduce risk, vulnerability, prevention, care, treatment and support so as to reduce the impact of the epidemic. All this can not be achieved if we fail to understand and address the issues of stigma. The Malawi HIV and AIDS policy document highlighted that “it is essential that the national response be based on the sound, current, empirically- based research”. This study aims to contribute to an understanding of HIV and AIDS related stigma and discrimination by exploring the experiences of people living with the HIV and AIDS in Malawi. Findings from this study may guide to come up with programs and interventions that may effectively reduce human suffering on people living with HIV and AIDS. The results might also help to come up with interventions that will help to stem the epidemic.

#### **1.4.4 Theoretical framework**

In the context of HIV and AIDS epidemic, stigma has become a central concept with an obvious universal salience among PLWHAs. However, efforts to conceive stigma as a sociological phenomenon are not standardized. A brief account is therefore given as an introduction to social theories that have guided the exploration in the current study.

Goffman, the pioneer of stigma indicated that historically the term stigma originated from the Greeks and it referred to bodily signs designed to expose something unusual and bad about the moral status of the signifier. He defined stigmatization as a social construct that significantly discredit an individual in a category of people available to him. He further stated that, stigma should be seen as a language of relationships(19). He indicated that stigma can be in a form of physical deformity or blemish of individual character or transmitted through lineage and contaminate members of a family. His

description of this attribute indicated that the possession of it reduces the bearer from a whole to a tainted and discounted being. He further claimed that on this assumption the normals exercise varieties of discrimination that reduces the stigmatized life chances. Goffman further dichotomized the persons with a stigmatizing attribute as discredited or discreditable persons. He defined a discredited person as someone whose difference can be spotted on first contact, and discreditable as someone whose difference can not be noticed on first contact.

Following the publication of Goffman's work on stigma in 1963 a lot of refinements and elaboration to the themes that he had introduced had appeared in a wide range of stigma literature.

Jones et al (1984) elaborated on Goffman's work, he defined stigma as a "mark" that links a person to undesirable characteristics such as stereotypes in a social relationship. He further distinguished six dimensions of stigma that included; concealability (That is the extent to which the mark is visible), course (pattern of change over time usually shown by the mark), disruptiveness (does it block or hamper interaction), aesthetic (extent to which the mark make the possessor ugly or repellent), origin (circumstances on the origination of the mark) and peril (kind of danger posed by the mark and its seriousness)(20). Jones emphasized on the influence of these dimensions in social relationships.

Link and Phelan (2001) conceptualized stigma as a co-occurrence of the following; labelling, stereotyping, separation, status loss and discrimination in the presence of power (21).

Aggleton and Parker (2003) conceptualized stigmatization as a social process that can only be understood in relation to power and domination. They have argued that stigma is not a "mark" or "an abstract" on an individual but a social process in a part of complex struggle for power that lies at the heart of social life. In their framework, they encouraged researchers to go beyond seeing stigma as a "thing" which individuals impose on others but to look at it in broader social, cultural, political and economic forces that stigma, stigmatization and discrimination as social processes inherently link to the production and reproduction of structural inequalities(22).

#### **1.4.5 HIV/AIDS and Stigma**

In general, it seems there is a consensus in the concepts that stigma is an attribute that discredit the stigmatized groups. The diagnosis of HIV or AIDS can be a discrediting attribute. The beliefs that surround HIV infection among others; means of transmission and origins of the virus may contribute to this stigmatizing process. The available literature has shown that persons believed to have HIV or AIDS suffer blame and social exclusion. Merging the types and dimensions of stigma as described by Goffman and Jones et al, Alonzo and Reynolds (1995) suggested that people living with HIV and AIDS are stigmatized because 1) their illness is associated with deviant behaviour. 2) The infection is viewed as a responsibility of an individual for contracting the virus. 3) It is contagious therefore people consider it as a threat to the community. 4) it is associated with un desirable death, and lastly 5) It is not well understood by religious beliefs and lay community(23).

The exploration of stigma in this study has been guided by a combination of bits and pieces of the presented theoretical frameworks underpinning on the socio-cultural factors that links stigma and stigmatization to production of structural inequalities in addition to the types and forms of stigma that were delineated by Goffman and Jones et al.

## **Section: B**

### **Chapter 2.0: METHODOLOGY**

#### **2.1 Research setting**

This study comprised of two categories of study participants that included; People Living with HIV and AIDS (PLWHAs) and key informants. The PLWHAs were enrolled at Lighthouse clinic and the key informants were enrolled from different professional backgrounds and different settings. The key informants were people who were working directly or in directly with People living with HIV and AIDS.

The category of the PLWHAs was recruited at Lighthouse clinic in the urban setting of Lilongwe district. Taking into consideration the sensitivity of the topic under study, this research setting was chosen because it had a potential of providing maximum variation of participants required to achieve the study's main objective without compromising their privacy and identity.

In addition to the provision of maximum variation of the study sample it also created other avenues of data generation through observations and participation in other activities that took place at the clinic. Though this was the case the clinic was an entry point to find study participants. Those who showed interest to participate were given options to choose venue for the interview and most of them chose the clinic setting except for one participant who was interviewed at her home.

This clinic serves people from Lilongwe district, the capital city of Malawi and a few others from other neighbouring districts. It is estimated that Lilongwe district has a total population of 1, 346,360 people. It has 6,159 square kilometres of land(24). Lilongwe is divided into three localities; urban, semi urban and rural areas. The urban population comprises of people of different ethnic background that includes people from all the 28 districts in Malawi. People migrate to the urban settings for employment, studies and other business.

I had worked at this clinic on a part time basis as a general nurse as well as research assistant between June 2003 and December 2003. My previous experience helped me to integrate into the system within

a short period of time. However, I was cautious that my familiarity with this setting could not have had a major influence on the generated data since it is easy to overlook matters of relevance to the topic in situations like this.

## **2.2 Overview of the clinic history**

This is the first clinic established in Malawi specifically for the treatment of HIV and AIDS cases. The clinic is situated on the campus of the Lilongwe Central Hospital (LCH), one of the major referral hospitals in Malawi. It was established in 2001 by staff members from the medical department at LCH following a realization of a need for HIV/AIDS care and support, for both in-hospital patients and patients in their communities. This was a follow up to the consultation with PLWHA who showed interest in having a special clinic for HIV and AIDS cases.

Their main aim was to provide quality care and counselling and to improve the quality of lives of people infected and affected by HIV and AIDS, including the terminally ill in areas around the clinic setting. To achieve this objective, the clinic provides comprehensive range of services and these include; Voluntary Counselling and Testing (VCT), clinical services that includes ARV, primary care for opportunistic infections, palliative care and community home-based care.

## **2.3 Clinic operations**

The clinic serves about 200 people per day. Out of this figure, 180 are subsequent patients and 10 are new PLWHA's coming for their booking visits. Subsequent clients report to collect their monthly prescription of ARVs and clinical assessment. The assessment is conducted by trained clinic nurses, during this assessment participants are screened for any problems that may arise because of ARVs. For some who present with health problems are referred to the clinicians.

Every morning numbers are distributed to patients who line up waiting for the clinic to open. Patients start lining up for the numbers as early as 3. 30 am in-order to return home or go to work in good time. So often people who came after 7.00am could not find numbers and were sent back and told to return the following day. Some who were coming from a far had to spend a night at the guardian's shelter to make sure they get a good number in the queue the next day. A discussion with the clinic staff indicated that plans were underway to increase ARV sites however staffing in those sites was

identified as a challenge. The plan was to integrate the ARV component into other clinical services in health centres and extend one of the hospitals in town to cater for ARV services.

The clinic operates from Monday through Friday from 8.00am to 16.00 pm. The clinic staffs gathered for morning meetings from 7.45am to 8.00am every working day except on Thursdays. On Thursdays they had departmental meetings and their meetings could go up to 8.30am and this delayed clinical activities. The clinic has four clinical rooms and four clinicians working on daily basis. It has a day observation room with 8 bed capacity. Patients who could not sit in the queue were sent to the ward where they were given a bed to wait for the clinician's round.

The clinic had five clinic nurses and four home-based care nurses. The five clinic nurses shared responsibilities of screening subsequent patients, blood draws, the ward activities and Information Education Communication (IEC) activities. Mondays, Wednesdays and Fridays the IEC offered morning health talks for the patients on different health issues. Wednesday lunch time ARV adherence counselling was offered to the patients. On Tuesday and Thursday lunchtime group counselling was offered to new patients who were to start ARVs.

The clinic receives clinicians and nurses from other institutions to help with the workload (25). The clinic also serves as a teaching area for clinicians and nurses from other institutions on ARV and primary care. In return, the trainees help the clinic activities when they are attached to the clinic for practical experience.

## **2.4 Research Methodology and Approach**

Research literature has shown that the purpose of the study determines the methods that can be used for data collection(26;27). Denzin (1994) indicated that studies that look for measurement and causal relationship between variables go for quantitative method while studies that look for social constructed nature of reality go for qualitative method(28).

The main aim of the current study was to explore the experiences of living with HIV and AIDS in the Malawian urban setting with a limited focus on stigma. Theories about stigma have shown the



complexity of this phenomenon. The reviewed literature indicated that it is difficult to unpick stigma as something that exist out there since it occurs in social processes. Therefore, understanding of this phenomenon required the researcher to learn about meanings that people attach to social processes, events and structures of their lives as they try to connect these meanings to the social world around them. In regard to this need, qualitative method was found suitable to achieve the goal of the study (29;30).

The study employed an ethnographic method of data generation in regard to the exploratory nature of the study question. Bryman (2001) noted that in ethnographic studies the researcher immerse him/herself in a social setting for a period of time, observing behaviour, listening to what people say in conversations, asking questions, collection of documents of interest and relevance to the study and conducting interviews(31). This is what I tried to follow to capture the complexity of HIV and AIDS stigma and stigmatization in the Malawian urban setting.

I triangulated the following methods; observations at the clinic setting, discourses analysis that included; analysis of conversations, collection of documents that included clinical counselling scripts and guidelines, following issues on media (news papers, radio, television) and conducted interviews with key informants and PLWHAs. The use of multiple data generation avenues was done purposefully. This was to help clarify meanings in order to gain more holistic view of the phenomenon under study as seen by different actors(28).

## **2.5 Study population**

The study population was divided into two categories; the PLWHA and the key informants as already highlighted in the opening of this chapter. The PLWHAs were the core participants.

## **2.6 Core Participants**

This category comprised of 8 women and 7 men of different ethnic backgrounds. The core participants' age ranged from 23 to 54 years. All were Christians who belonged to different denominations. Only four were employed at the time of the interviews. Some reported of premature retirement because of ill health. All the participants had gone to school, the lowest grade was standard

3 and the highest attended college. Out of the 15 participants 7 were married, 5 widowed, 1 divorced, 1 single and 1 separated. Twelve participants were living in higher density populated areas in the city, two lived in semi-urban areas and only one lived in a medium populated density area.

HIV and AIDS diagnosis was a basis for study participation. I made sure that I recruited participants who were over 18 years of age in accordance with the requirements of the Malawi ethical review board. To achieve the study objectives, participants were enrolled at different stages of their illness. The core participants' category comprised of people who had learnt of their HIV status but had never suffered from any AIDS defining illness, some who suffered from AIDS defining illnesses and were in the process of recovery, and others who recovered from an AIDS defining illness and were back to their normal duties. Efforts were made to enrol participants of different social classes, ethnic and religious backgrounds. People who had seemed to be of higher class did not show interest to take part in the study. They indicated of being busy when they were approached to join the study. This might have an effect on the study findings since almost all the participants came from a low social class. There is no representation of higher social class people.

## **2.7 Key Informants**

This category comprised of 11 key informants, 5 women and 6 men. Their ages ranged from 28 to 51 years. All were married except one who indicated that her partner died from an AIDS related illness. This category included people from different professions except two who were guardians for HIV and AIDS patients. The rest were working directly or indirectly with people living with HIV and AIDS. The category comprised of people from Media, government institutions (policy project), religious institutions (both Moslem and Christian institutions), health sector (clinic staff), and HIV and AIDS support group leadership. The lowest level of education in this category was primary school leaving certificate and highest was Masters. The participants in this category had a wider experience of working with HIV and AIDS programs. Two of them were known HIV positive cases. Some were HIV and AIDS program managers who were running HIV and AIDS community programs within Lilongwe and in other districts in Malawi. Those from the religious institutions were heading HIV and AIDS programs that were run by their institutions. The one from the Media was one of the people responsible for the production of radio programs called breaking the silence where people living with HIV share

their life experiences. The period of key informants experience in this field ranged from 2 to 18 years that excludes the guardians for the patients. The nature of work for most of these key informants took them to almost all the districts in Malawi. Therefore, the information that they had given in this study is not only from their experiences in Lilongwe city but other districts also including rural areas.

## **2.8 Sample selection and justification**

Maximum variation, a strategy of purposeful sampling was used to identify study participants. Selection of information rich cases was preferred to learn more about the issues of central importance to the purpose of the current study (32). This yielded insights and in depth understanding in the stigma related issues. A total of 15 PLWHA participated in the study. Participation in the study was voluntary. A short talk that highlighted the purpose and the objectives of the study was given to patients in the Information, Education and Communication (IEC) room at the clinic. Those who volunteered to participate, an agreement on convenient time and date was made for the interview.

In addition to the 15 PLWHA, 11 key informants were recruited. The researcher made consultation with staff from National AIDS Commission resource centre to help with the selection of information rich key informants on the topic under study from religious institutions and other areas. They gave a list of organization and contact details of people who were dealing with HIV and AIDS activities in Lilongwe. Other key informants were identified along the process. Their nature of work was the criteria for their participation. The effort that was made to contact people who hold key positions was done purposefully to enrich the data collected.

The aim of the study was to explore the depth not the breadth of the experiences of living with HIV and AIDS. With the purpose of the study in mind, time and human resource limitations, a small sample was selected in order to learn more from individual experiences. As such the findings of this study can not be used for statistical generalisations instead inferences can be made from the findings. However, the use of general discourses that came out through the media, generally available meanings, terms and conditions in the interpretation of individual's accounts may indicate that the current study has at least

the potential to shed light on the experiences of people beyond the limited sample of the core participants.

## **2.9 Field arrangements**

Two research assistants were hired to help with transcription and typing. These two had previous experience with transcription of qualitative interviews. Therefore, I only took a day to brief the assistants on the objectives of the study and the study protocol and discuss on transcription since they had knowledge on verbatim transcription.

Clinic staffs were briefed on the study protocol and arrangements for recruitment were made. Patients were told about the study in the Information education and communication room (IEC) following morning health education talks. Two interviews were scheduled per day. Core participants were given refreshments during the interviews and transport reimbursement at the end of the interviews.

## **2.10 Data generation techniques**

Observations, semi-structured interviews and analysis of public, semi public and clinical discourses were the avenues of data generation for this study. Observations of clinical activities were conducted between the months of September and December. That included; observations in counselling sessions, day ward activities, interaction between patients and health care workers, interaction between patients and their guardians and in health education teachings. Interviews were also employed to generate data from the PLWHAs and the key informants. A total number of 25 interviews were conducted with 15 PLWHAs. The analysis of discourses included data from informal and formal conversations and relevant information from the media and clinic discourses.

## **2.11 Observations**

Grbich (1999) defined participant observations as data collection tool that involves the researcher spending time in an environment observing behaviour, action and interactions to help understand the meanings constructed in the environment and make sense of life experiences(33). Since HIV and AIDS diagnoses are reported to be “stigmatizing” attributes this method was chosen to capture and understand the meanings that are attached to these diagnoses within the clinic context. This was to help contextualize peoples’ shared experiences.

Observation was identified as relevant to the aim of the study because it creates an opportunity to see of relevance to the study topic that may routinely be taken for granted. In this study, observations were conducted in counselling session, health education sessions and interaction between patients and staff, among patients, and patients and their guardians. The interactions were observed to understand the social processes that may indicate the meanings attached to HIV and AIDS diagnosis. This was also followed in conversations among patients and members of staff, patients and their guardians. Most often the meanings that were captured were related to the moral values attached to the individuals infected.

Efforts were made to participate in different counselling sessions. The VCT coordinator granted permission but access was only given to three counselling sessions that were conducted by one female counsellor. The counsellors reported that the clients denied presence of a third person in the sessions. Teaching materials that were posted on the walls in the counselling department also conveyed some meanings attached to HIV infection.

I also participated in a counselling course that took place at the clinic during field work. This was a six weeks training course and the researcher only attended on a discussion about the languages of HIV and AIDS. That helped me to capture metaphors that people use in reference to HIV infection and the individuals infected.

I had a chance to participate in group therapies at two HIV support groups that I had visited. These visits helped me to learn more of the negative experiences that some PLWHAs in these groups had experienced in different settings. I was allowed to take notes in the course of the PLWHAs discussions.

## **2.12 Qualitative interviews**

Kvale defined research interviews as a specific form of human interaction in which knowledge evolves through a dialogue(34). Interviews in this study were chosen because they create an access to interviewee's world, and their lived meanings (ibid). This enabled me to understand the meanings constructed by people regarding their experiences of living with HIV or AIDS. The interviews also

helped to capture experience that happened at some previous point in time which could not have been captured through observations.

Interviews were conducted with PLWHAs and key informants from September to December 2005. The researcher conducted these interviews herself to make sure all the relevant topics were covered and that probing to themes that seemed relevant in the interviews was done appropriately. In total 25 formal interviews were conducted with the 15 PLWHAs and 11 interviews were conducted with the key informants. In addition to the formal interviews 6 PLWHAs and 4 key informants were contacted on phone to clarify on issues of relevance to the topic that were identified from the participants' narration in the second interviews. The plan was to conduct repeated interviews with the core participants until no new themes emerged from the follow up interviews. This was not the case with some of the participants who were reported to have been relocated at the time the researcher tried to contact them for follow up interviews. At the beginning of each interview participants were asked to give their demographic information (refer appendix 1).

### **2.13 Core participants' interviews**

Repeated interviews were opted for in this category to gain a deeper understanding of the experiences that participants have had of living with HIV or AIDS. This gave more insight to the meanings that participants attach to their life experiences when they tried to relate their experiences to the contextual social order (religious, traditional beliefs and socio institutional structures such as family members' rights and obligations, gender issues imbalances).

The interviews were conducted using interview guides that consisted of semi-structured open ended questions (refer to appendixes 2A). The guides were prepared in English and later translated into Chichewa, Malawi's local language. The Chichewa guides were back translated into English by the research assistants who later suggested some grammatical changes in the Chichewa version to ensure that they carried similar meanings to the English versions. Following the changes the guides were piloted to check understanding of the questions with two known PLWHAs.

At the beginning of each interview, participants were given options to make a choice of language that they felt comfortable expressing themselves with. Almost all preferred Chichewa but during the course of the interviews some participants mixed Chichewa and English languages.

The flow of the interview was not directed by the outline of issues on interview guides but the response from the interviewee. Probing was done wherever the researcher saw it necessary. The interviews lasted between 37 to 88 minutes. All the interviews were recorded with interviewee's permission.

During interviews the researcher found it difficult to write detailed notes and keeping focussed on the interviews at the same time. As such very short notes were taken and expanded later at the end of the interviews. Follow up interviews were scheduled according to convenient time to the researcher and the interviewee. Some participants gave their contact details such as phone numbers and landmarks to where they stayed. All the interviews except one took place at the clinic and participants opted to have the second interviews at the clinic.

Time for the second interviews varied depending on the issues that needed clarification and new experiences from other participants.

#### **2.14 Key informants interviews**

Interviews with the key informants were conducted to explore their perspective on the topic understudy. The interviews lasted between 40 minutes to 2 hours. Tentative guides were developed in English and later translated into Chichewa. Additional topics were made to the guides depending on the nature of work of the informant. All the interviews were recorded with the informants' permission and the interviews were conducted at the key informants' place of work. The guardians for the patients were interviewed at the clinic premises.

#### **2.15 Discourse analysis**

Discourses are dynamic dialogues in which meanings are socially and historically produced, reproduced and transformed in interaction(35). In this study discourses were identified as useful since they indicate the way in which particular set of linguistic relates to a phenomenon and this depicts the frame in which people comprehend the phenomenon. Bryman (2004) noted that a version of an object

comes to constitute it(36). In this case learning about HIV and AIDS in the forms of communication gave a picture of how these diagnoses constitute a particular view of the social world.

Discourses of relevance to the study topic were captured in six Malawian news papers, television and radio programs. In addition, data from the observations, conversations with clinic staff and patients at lighthouse clinic and texts from the interviews were also analyzed. The programs that were followed on television and radio included; youth programs that mostly focused on prevention; that is abstinence, being faithful and use of condoms, radio diaries where PLWHA were featured to help give a human face to HIV and AIDS and also Public health messages, both verbal and non verbal.

The data from these sources highlighted on how people understand HIV and AIDS. Some perceived it on religious grounds, medical grounds and others on cultural beliefs. This determined how they justify potential candidates; these are people who are thought to be at “high risk” of contracting the virus and reasons why people get HIV. This has helped to give a meaning to some of the experiences that participants shared in the narration of their lived experiences.

#### **2.16 Researcher as a research tool**

My role in this study could be described as an informed outsider. My previous experience of working with PLWHAs as a counsellor as well as a research nurse partly gave me an insight of the experiences that PLWHAs encountered. My counselling skills made me comfortable and skilled to get people talk about their experiences. This was through use of communication skills that included: attentive listening and use of minimal encouragers. However, this might as well have an influence on the interviewee’s response to some uncertain extent.

While in the field I thought of taking an HIV test. However, it proved to me that for one to go for an HIV test is not as simple as some of us, “health professionals” think when we encourage others to go for testing. My interaction with other health professionals indicated similar experience. I have also experienced the impact of HIV and AIDS among patients that I have interacted with, relations and friends. Through these experiences I became more informed on the challenges that PLWHAs go



through but I had never thought of exploring the depth of these experiences and the social factors that underlies the experiences.

### **2.17 Data handling and Analysis**

The researcher conducted all the interviews herself to make sure all salient topics for the interviews were covered and that appropriate probing in relation to the topic under study was done. Soon after interviews the tapes were listened to for a few minutes to make sure the interviews had been recorded and that they were audible. All the tapes were labelled for easy identification. The labels included; date of interview, participant category and participant identity number.

After interviews the tapes were handed to the research assistants for transcription. Transcription was done in English. Two more research assistants were hired to help with transcription. This was because the two assistants who were hired earlier on could not keep up with the pace of the interviews. Soon after transcription the transcripts were sent for typing. My task was to compare the typed transcripts and the recorded interviews to make sure that the interviews were transcribed verbatim. In the course, the researcher identified some issues that were pursued in the follow up interviews.

Analysis started with development of study design. This was through selection of theoretical framework, research questions, criteria for the selection of study population and development of interview guides. After data collection process was completed, I continued with data analysis. I repeatedly read through the texts that were generated from the field observations, public discourse and interviews to come up with the themes. The process of data analysis used the objectives of the study, research questions to come up with the themes that helped with categorization of the data. A number of theoretical frameworks were merged as indicated earlier on to guide the analysis and the interpretation of the presented findings.

### **2.18 Ethical Consideration**

The Malawi National Health Sciences Research Committee approved the research protocol (refer to appendix 3). A brief talk about the study and its purpose was given in the IEC room following the morning health talks that are given at the clinic every morning.

The core participants who showed interest to participate in the study were given consent form to read on the details of the study and their rights to participate (refer appendix 4). The consent form included the purpose, objectives of the study, and data collection techniques. They were also told that participation was voluntary and that they were allowed to withdraw at any time without interfering with the help that they were receiving at the clinic.

Written consent was obtained from the core participants and oral consent from the key informants. Participants were assured that their identification details will be kept in secret and separate from what they will say during the interviews. Emphasis was also made on confidentiality of information that they were to give during the interviews. However, the participants were told that other research team members will have access to the information that they were to give in the interviews except for their identification details. Participants were given identification numbers which were used to identify individual tapes. It was only the researcher who could make a link between the numbers and the personal identification of the participants. At the beginning of each interview participants were asked for permission to tape record of the interviews and they all gave consent to the recording.

I discussed with the research assistance about confidentiality and privacy for the study participants and the information that participants gave in the study. The assistants were asked to sign a confidentiality form (refer to appendix 5).

I also asked for permission to participate in the two support groups that I had visited and explained the purpose of my research to the members of the support groups. Members were given options that they were allowed to leave or just listen to others if they were not comfortable with the presence of the researcher in their discussions. An explanation was given to them that whatever the researcher will learn from them will not be identified by individual names but the findings will be generalized. Similar explanation was also given to the members of the counselling training that I had attended at the clinic.

One participant explained during interviews that he was given employment termination notice because of HIV diagnosis. It was difficult for me to advise what he could do to protect his right to work. The PLWHA had done nothing at this time and explained that he did not know what to do with his case.

With regard to the formal ethics of recruitment and information procedures, I felt it as an ethical obligation to provide advice if needed and guide participant to available support services. Therefore, following this incident I developed preparedness to do so. I contacted the PLWHA and advised on how he could take up his issue to avoid losing his job.

### **2.19 Dissemination of findings**

At the end of data generation period, preliminary findings were presented and discussed with the clinic staff. An emphasis was made that the findings were not conclusive there might be some changes in the final report.

The findings will be shared with government and non governmental organizations and institutions especially those that contributed to the findings. Findings will also be presented in HIV and AIDS research dissemination conferences.

## **Section: C**

### **Chapter 3.0: CONTEXTUAL BACKGROUND**

#### **3.1 The unfolding journey of life after HIV diagnosis**

This chapter presents a case of one of the PLWHAs who participated in this study. This case has been given in this thesis for two reasons; the first reason is that it highlights contextual social structures that have been considered important to the analysis and interpretation of the experiences that the participants of this study shared. The topics include; 1) religion and religious institutions, 2) sex and sexuality, 3) family structure and social relations, and 4) gender relations and roles.

The second reason is that this case highlights four themes that have been considered important to illuminate the experiences that were shared by the PLWHAs in this study. The themes include; 1) HIV, AIDS and culture, 2) the consequences of living with HIV or AIDS, 3) management of reputation in the community and 4) the “beginning of new life.” A brief account of what he narrated of his experiences after diagnosis has been given below.

A 30 year male PLWHA tested HIV positive in April 2003. He is a Christian member of Church of Central African Presbytery who had stayed in marriage for a period of about 2.5 years. He completed his secondary education and has done a course in marketing. At the time of the diagnosis he was working with a certain company in Blantyre which is Malawi’s major commercial city.

I asked him to narrate how his life had been since the time he was diagnosed with HIV. In response he started with saying that he has faced a lot of problems ever since he learnt about his HIV sero positive status. He explained that he had decided to go for testing because his wife had spontaneous abortion.

He described how he had jokingly suggested to his wife that they go for testing together as a family but the wife refused. In response, the wife told him that his suggestion implied that he did not trust her. Later, he decided to go for testing on his own.

I asked him if he had ever thought that he had the virus in his body, he responded that sometimes he was worried because he used to have unprotected sex with another girl when he was in school. Nevertheless, he explained that at the time he went for testing, he did not expect to receive an HIV positive result. That made the situation difficult for him to receive HIV positive results as he narrated in these quotes;

It was a difficult situation for me. When going for testing I did not expect to be HIV positive.

My life in the past, I was not careless or having many sexual partners and I was wondering where I contracted the virus because I was very faithful to my wife so I was shocked. I was praying a lot and people looked at me as someone with good manners.

He further said that his main worry was on how the people around him would treat him with his status.

He disclosed his test result to his wife on the same day.

After being counselled at MACRO<sup>1</sup> I felt a need to tell her my status so that she could also go for HIV testing.

I disclosed to her on the same day because of the way we were staying. I felt it was good to do so.

He said that on the next day the wife went to her mother and disclosed her husband's HIV sero status. The mother instructed her daughter to leave him. I further asked how long it took to happen from the time the wife informed her parents to the time she decided to move out of her marital home.

This was happening simultaneously, I disclosed my status like today and the following morning she went to her parents and told them my status then she came back home with her brother who assisted her to take all her personal belongings.

He explained that after disclosing his HIV status to his wife, he had decided to accept his status and move forward with life. However, things changed and his plan did not materialize when his wife left him. He claimed that when he tried to contact his wife, he was told that her mother had instructed her not to communicate with him any more.

Apart from his wife it took him three months to disclose his HIV sero status to his parents and relatives. However people around him knew that his wife had left him because he had tested HIV positive. When his friends at work and in the neighbour hood heard about this they started giving him different treatment as he narrated in the quote below;

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<sup>1</sup> Malawi AIDS Counseling and Resource Organization

(...) the people who were chatting with me were showing that they were discriminating me. If they were chatting and when I popped in they would immediately stop the conversation. I could really see that they were talking about me.

When he tried to inquire of what his friends were discussing, he was told that he came when they had finished.

My family and our neighbour used to eat together but when they knew that I am HIV positive this habit stopped completely.

The treatments that he had received disturbed him a lot, he later decided to quit his job and relocate.

Eeh, If I reached a point of changing a city, it was painful really painful. I even decided to quit my job. They were looking at me as someone useless, a mentally ill with very bad smell.

He reported that sometimes he could have suicidal thoughts because of the treatment that he was receiving from his friends and neighbours. He further reported that whenever he felt like people had given him unfair treatment, he thought that he was being treated in such a way because of his status.

When I asked him why he had to stay for three months before he disclosed his HIV sero status to others, he reported that having HIV is a shameful thing as it relates to moral and sexuality issues. Therefore he thought he needed to keep it private.

At that very first time I was taking the issue of having the HIV virus as a taboo which needs to be kept secret.

In our society when people hear that such a person is HIV positive it is a shameful condition. As such it does not give good impression. You are taken as someone who has been careless with your life.

The researcher sought clarification on what he meant by “careless with your life” and he clarified that it meant being promiscuous, “going out with a lot of women”.

He claimed that the life transactions that had happened since the time he came to know his status, made a lot of changes in his life. He said that he was not able to interact with other people in the same way he used to interact with them before. He stayed for 3 months before telling anyone apart from his wife. During these three months he was not able to chat with his friends in the same way he used to chat with them previously. He was spending days without food. He was leaving his house in the morning and came back in the evening without eating anything.

My health was deteriorating and I felt that maybe if I share my problem with someone else will be in a position to give me some directions. So I felt that I needed to disclose to my mother who supported me a lot, psychologically and with some food since I stopped working.

He explained that he called his mother who stays in the capital city and told her that he had stopped working and had planned to join them to take a rest. His mother asked for the reasons why he had decided to stop working. As he puts it in the following quote;

Apart from my wife I did not disclose to anyone else. It took 2-3 months, when I stopped working I called my mother that I have stopped working and I am coming back to Lilongwe to rest. She tried to probe on the reason why I decided to stop working and I told her it's a sensitive issue which I can't discuss on the phone. So when I came back I told her my status together with my Uncle, after three months.

This is the time that he had to quit his job and relocated from Blantyre to Lilongwe where he joined his parents. That is where he explained to his mother and Uncle of what had happened to him. He claimed that when he disclosed his status to his parents and relatives he had peaceful mind because of the support that they were giving him. He further said that his mother encouraged him and gave him psychological support and she also provided him with the necessary food that he was advised to eat at the clinic.

When he had joined his parents in Lilongwe, he applied for a job and he was invited to go for interviews. Before they offered him the job he was asked to go for HIV testing. Since he knew his status he thought of telling them right there.

So I decided to disclose my status to them and they told me that they couldn't offer me a job. As of now I am not working and I am afraid to go to these other companies to look for a job because I feel that I will be told the same thing to tell them my HIV status.

I asked him what it meant to be infected with HIV. He reported that at first he thought being HIV positive was a death sentence as he puts it in the following quote;

(...) when I was found to be HIV positive I had some suicidal thoughts or I was thinking that being HIV positive was a death sentence.

However, he indicated in his narration that after diagnosis he has discovered that having "HIV is the beginning of new life."

Aah, as of now I feel that if you are found to be HIV positive is not the end of your life, but the beginning of new life.

With references to all that he had gone through since he received his HIV diagnosis, he has deduced that having HIV is not the end of life but “the beginning of new life”.

Receiving of HIV diagnosis seems to be a hard time whereby one has to take stock of his past life. At the same time tries to focus on the future that does not seem to be clear with this “stigmatizing” and incurable disease. As such there is a need for collective efforts to instil hope in the individuals infected. It seems that it is not easy for one to carry this burden alone. That could be the reason why the participant in the presented case had to relocate to join his parents in Lilongwe for support since in Blantyre he did not find any kind of support.

I also asked what he thought about other people’s impression of people living with HIV and AIDS. He narrated that it is not only the impression but they do talk a lot. He referred to gossiping in the communities. When one has HIV, it becomes an agenda for gossiping whereby one’s morality is questioned and his ways analyzed to find out where he made a mistake for him to contract the Virus.

Eeh, they do talk a lot not only having the impression. (Pause)They take you as someone who has been promiscuous and going out with a lot of women in your life. They think that you are just waiting for the day when you are going to die. Sometimes they will take you as someone who is depending on ARVs to survive otherwise you could have been dead already.

I further asked why he thought people treat PLWHA in this way. He reported that people mistreat those living with HIV because they were taught that the chief mode of HIV transmission is sex. As such a person with HIV is taken as somebody who has been promiscuous. The other risks that might lead one to contract the virus are disregarded, most often focus is on sex as a principal mode of transmission.

He had appreciated care and support that he was receiving from his family members, as well as from the church members and the clinic. He reported that the church members visit him when he gets sick and they take him as “a normal person just like them”.

I do get support from the church. They are able to come and visit us in our location when they hear that such a person is sick. We pray together and sing some choruses together. They take you as a normal person same like them. They don't say that this person is HIV positive when praying, no.



He said this against the claim that other people make that churches condemn people living with HIV and AIDS as sinners. He further explained that he was not sure if the preachers condemn people living with HIV and AIDS as sinners but that his perception on the church teaching is that they condemn the behaviours that predispose people to contracting the Virus. However, he expressed concern over some jokes that sometimes his friends made of him.

(...) as for my friends there are some changes like when I go for social football they would crack some jokes to say, that one should not be included because he may die in the ground. I don't know whether they talk in this way because they know my status. These jokes are really painful to me.

When he was asked on how he has managed to cope amidst the problems that he has gone through, he explained that he had managed because of the understanding of his family members, encouragement from fellow church members through prayer, care and counselling support that he receives from the clinic and sharing information with others with similar problem like him when he comes to the clinic.

At the time of the interview he reported that he was planning to join a support group, where he would have a chance to know others with similar status just like him.

I have decided to join them because you know each other that you have similar status, you are able to share experiences, interact freely and share new developments on HIV and AIDS and also part of work. Like the way I was treated at my work place they are able to intervene and come up with some solutions on how you could be compensated. These things happened to me and I did not know where to go so that I could be assisted. They could be able to take up the issue for me.

This was also noted in the narration of PLWHAs at the two support groups that I visited during data generation period.

In appreciation to the care that he had received at the clinic he was encouraging others to go for VCT and gave them counsel on the benefits of knowing one's status

(...) we<sup>2</sup> are able to tell them that knowing your status is not the end of everything but the beginning of new life. Drugs are available which will prolong your life. After convincing them some of them do come to access the care and support.

After going through all these problems, he seemed to have managed to cope and seemed to have reached to a point whereby he has accepted his status and has taken it as a part of him. He is now

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<sup>2</sup> In one of the quotes he used "We" refers to the PLWHA category.

advising others on what to do when they test HIV positive to continue with their life and try to live their life to the fullest. He tries to set a good example to others with similar problem (role model). This is an indication that though HIV diagnosis brings social death to the individuals infected, there is life still after receiving an HIV diagnosis. However, this is not uniform to all who gets HIV diagnosis there are others who can not handle such stressful situations as such they do not reach this far.

In his narration he defined receiving of HIV and AIDS diagnosis as the beginning of new life. Here he made a reference to the end of life as he had known and lived it to forging a head with a new role and identity. We can as well abstract the meaning of “beginning of new life” from what he narrated.

The story has shown that since he had received HIV diagnosis his life changed. He was a man who was working and meeting all his needs before he went for HIV testing. Though he was not sick at the time he had learnt about his status, the knowledge of his HIV sero status alone had incapacitated him that he was not able to fend for himself anymore. Since he quitted his job, he was depending on his parents to provide for his needs.

In addition, he had to take into consideration some new issues in his day to day life which were not there previously. That includes; Information management – who should know, who should not know and why? Make sure he lives up to the instructions that he had received from the clinic to stay health. The instructions among other things included good dieting which needed a lot of money. Lastly he had to find means of coping with the partner’s and friends’ response to his status.

The problems that he faced fit very well with the literature that states that HIV and AIDS is not merely a medical problem but a complex social problem too(37). One may ask why people are treated in such in-human way at the time that they need social support most. While others can ask why is it that HIV infection or AIDS is a “shameful condition” as it has been reported in the told story?

Alonzo et al (1995) claimed that PLWHAs are held responsible for their infection as it is mostly associated with deviant behaviour. The illness that comes out of such behaviours discredits people’s claim of being moral characters. He further claimed that stigmatizing attributes derives from culturally

rooted meanings to which various forms of deviance are referred to(38). In addition, Aggleton and Parker (2003) stated that these stigmatizing attributes have a history in a particular culture that influences its shape and when it appears (22).

Taking these claims into consideration, should we just endorse them that this could be the case for the experiences that the PLWHAs shared in Malawi? Or do we need to understand the cultural context in Malawi before we can come up with our conclusion?

Since literature has clearly stated that stigmatizing attributes derives from cultural embedded meanings and these meanings differ from culture to culture. Given this as a point of departure, we need to understand other dimensions of the Malawian culture and its social structures to get a clear view of what deviation means in this setting.

The narration in the presented case has highlighted that PLWHA's are given such in human treatments because transmission of HIV is associated with sexuality issues. The narration indicates that people consider less the other modes of transmission or factors that might have predisposed the person to contracting the Virus. Instead they just think of the individuals infected as people who have been promiscuous "careless with life." In regard to this, there is need to understand sex and sexuality issues in relation to HIV and AIDS in this context. In addition we also need to understand gender relations and roles and family structures and relationships. Understanding of these issues will give us a picture of why he had to quit his job and relocated to join his parents and relatives. Why of all the people he had chosen to confide in his mother when his wife was not there for him.

As he continued with his narration he mentioned about his religious life. He reported that he was praying a lot before HIV diagnosis and people looked at him as some one with good manners. His narration has shown that being HIV positive led him to lose dignity that was accorded to him as a religious person. In regard to this, there is need to understand the relationship between religion and HIV and AIDS. This will help to highlight on the reasons why the knowledge of his HIV positive sero status raised worries in him about how the public will respond to his status being a religious person.

The selected topics are relevant to the experiences that almost all the participants shared in this study. These topics are discussed in detail in the next section to help give an overview of the context that shaped the experiences that participants shared in this study. This helps to give a meaning to what the selected themes will illuminate on the experiences that were shared by the study participants.

### **3.2 Social and Institutional Structures**

The told story has highlighted some issues that need further clarification to help make sense of the experiences that participants shared in this study. Therefore, this section gives a detailed account of the issues that the story has highlighted that includes; family structures and relationships, gender roles and relations, religious and religious institutions and lastly sex and sexuality issues. These issues are interrelated and the issue of gender cuts across all the other issues. As such discussion of issues that relates to gender roles and relations will cut across the discussion of the other issues. The discussion includes abstractions from literature, study participants' narrations, media discourses and researchers experiences of being a Malawian.

#### **3.2.1 Family structures and social relationships**

In Malawi, extended family is the first and foremost kinship group. The families comprise of blood relationships and others members joined by marriage. These relationships are deeply rooted in socio-cultural environment. The families are either patrilineal or matrilineal; Matrilineal is mostly found in the southern and central region while patrilineal is mostly common in the northern part of Malawi. The difference between matrilineal and patrilineal revolve on issues of marriage and property inheritance rights (39). In matrilineal the family is an integral part of the wife's lineage while in patrilineal the family is an integral part of the husband's lineage.

In the rural Malawian setting the extended families live in loosely connected groups of homesteads forming small villages within the big villages(40). The relations in the extended families play different roles in the family. Mtozi (1999) stated four important roles that are performed by the father, child, mother and the grannies in the African families. The responsibilities that he stated fit very well with the responsibilities in the Malawian families. These include; headship of the family which is the responsibility of the father, who is also responsible for providing economic needs of the family members and takes care of the well being of the family. The mother is responsible for upbringing

children and care for the husband and the other family members. Grand parents help with upbringing of children while the children helps parents with household and other duties(41).

Traditionally extended family members are a part of decision making in some events that take place in one's family. Mostly in the Malawian setting the people who take part in the decision making are either paternal or maternal Uncles or Aunts depending on the type of family. Often the couple does not make all the decisions for their family. This is more common in issues that relates to child bearing.

Depending on the type of family if it is matrilineal, the father plays a minimal guardianship role and the brother of the wife is responsible to look after the welfare of the sister's family. However, this is changing due to urbanization and the devastation impacts of HIV and AIDS. Among other responsibilities the brother to the wife is supposed to look for treatment for the sick members in the family, ensures that his sister behaves in a culturally acceptable way, arranging marriage for his sisters, helps to sought out marital problems and make sure that the couple gets children for the continuity of their lineage(42).

Children are greatly desired in the families and are regarded as a guarantee for the continuity of the family lineage as well as survival of marriages(42). This has posed some challenges to families that have tested HIV positive. Some women in two support groups that the researcher visited during data generation period claimed that they did not plan to give birth when they tested HIV positive. Most of them claimed that it was the influence of their husband's relations. In such cases when women try to negotiate with their husbands to consider their status and the after effects, some do not succeed though the husbands know about their problem. However, this does not put women only in dilemma but men too. This happen in-cases when the family did not disclose to other family members about their problem. This can be quite stressful to the men because they are the ones who are approached by the family members to find out what is the problem for them not to have children. This was confirmed by a Malawian Pakachere radio play that is sponsored by Population Services International. In this play a husband and wife who knew about their HIV positive status agreed not to have children in fear that they may give birth to sickly children. They lived for quiet some time, later the husband's Uncle visited them. He asked his nephew on what was preventing them from having children. He had no

answer to this question instead he was just talking to himself on how he could handle his situation when his Uncle had left. In such cases if decisions are made to please the family members, most of the times women are the one's who suffer the consequences.

In cases of life events extended families serve as safety nets for the affected members(43). The African family has been reported to be a major structure that is traditionally responsible for caring for the health of its individuals(41). This holds true Malawian families where care for the sick and orphans is primarily a house hold responsibility.

With the coming of HIV and AIDS the social ties have been overstretched to meet the demands of the households(43). The increased burden of the affected members is now felt beyond the house hold experiencing the illness by relatives or neighbours who may share the responsibility of taking care of the sick(44). A lot of people are getting sick in the families most of they suffer for long periods from AIDS related illnesses. This creates loss of labour, heavy burden to the families and food insecurity to most of the households. This is because most of the time is spent in caring for the sick instead of concentrating on family developmental issues. HIV and AIDS have brought economic problems to the families since resources are diverted to the care of the sick. A lot of money is used to buy medication, transporting the sick to hospitals, funeral costs and food for the sick. In addition, the nature of the disease has increased number of orphans such that many extended families are not able to cope. These problems have put the extended families and social structures under strain(44). This has raised a heated debate between development practitioners. While others have argued that the extended family systems are disintegrating towards nuclear family, such that there is an increase in number of widow, childhood headed house holds and destitute children(45;46). some claim that most of the families are developing adaptive mechanisms with varying degrees of failure and success to cope with the demands(43). These practitioners have claimed that new strategies are adopted and others abandoned, most often adaptation to these demands depends on availability of material and human resources in the affected families (ibid).

In addition to the problems that the nature of HIV and AIDS has brought to the infected and affected families, a report that looked into the experiences of women living with HIV and AIDS in a South

African study has indicated that families are faced with a challenge of whether to accept or reject caring role. This is associated with the fear of “social contamination” of HIV and AIDS as it is commonly referred to as a stigmatizing condition(47). Hence these factors have brought either positive or negative impacts to the lives of people affected and infected with HIV and AIDS.

### **3.2.2 Gender relations and roles**

In Malawian culture women and men are given different positions in the society. The moment a child is born, it is treated on the basis of its sex and that shapes their adulthood responsibilities. Such that men are taught in a way that shapes them to be heads and decision makers of the families. Women are shaped in a way that permits their subordination to men and they are expected to be submissive to men’s decisions(39;48). Traditionally culture ascribes gender roles that are different for men and women. In most of the Malawian rural communities’ women and men are spatially separated, within the homes and immediate environment there are designated places that have undefined rules that demarcate places for men and women(49). Within the homes these places include; the kitchen and the veranda around that place is for women and girls whilst boys have their small houses at a distance from the family house where they spend their evenings and rest with elderly men during day time. This separation and intergenerational interactions permits girls to socialize with elderly women where they are taught household chores such as; cooking, caring for the other family members and the sick. Such activities mode girls’ behaviour and thinking towards serving men. This applies also to boys who socialize with elderly men and learn gender roles that are culturally ascribed to men. This difference has laid a mentality in boys that women are there to serve them(49). However, the spacing arrangement is not adhered to in the urban settings due to space and congestion in the homes but gender roles still remains un -equal in between men and women.

#### **3.2.2.1 Imbalance of power in decision making and women’s economic dependence on men**

The position of women in Malawian society is one of subordination and submission to men who are most often decision makers and bread winners, providing financial security for their families. Women are mostly on the receiving end of their husband’s decision. They are mostly working in the homes where their work does not generate money as such they are considered as people who can not own big property or a piece of land(50). Their primary role is always considered that of a wife and a mother.

Even if they are working and earn a living most often they are less recognized for their contributions(48). This has led most women to their economic dependence on men. As such it gives men more decision making powers and renders women to have limited control over their lives.

The women's economic dependence on men has often predisposed them to abuse of power by men. Women often live in fear that their husband's will marry another woman and this is condoned by the Malawian culture. These threats give women limited ability to protect themselves against HIV infections(50). This is consistent with what some of the women who participated in this study reported during the interviews. The women narrated that they were unable to discuss with their partners about safe sex when they learnt of their HIV sero positive status. Their narration also indicated that they failed to ask their partners to use condoms when they knew that they were at risk of contracting the virus through their husbands' extramarital affairs. Zulu (2003) in a study that looked into spousal communication about the risk of HIV in rural Malawi indicated that condom use is associated with extra marital sex. Asking for condoms in marriage even in cases where the spouse knows or suspects that the partner is having other affairs raise tensions that many spouses are not prepared to handle(51). Schatz (2005) argued that women's reluctance to suggesting condoms with their husbands could be related to the meaning of the request within marriage rather than lack of empowerment(52). However, this can not be generalized to all women whilst some women fail to negotiate because of the meaning of condoms in marriage others lack empowerment as indicated by some female PLWHAs above.

In most cases women do not make decisions on matters that concern their lives without the approval of their husbands. Informal conversation with study nurses who were working with one of the projects at Lilongwe hospital indicated that some similar cases in women who were participating in a clinical trial of Micro-bicide gel and condoms. This was a study that is looking into the effectiveness of gel in prevention of sexually transmitted infections that includes HIV. This study was in progress at the time of data generation for the current study. Some of the women who were participating in this study reported cases of violence from their partners and some withdrew their consent from participation. They gave reasons that in the first place the women did not inform their partners of their interest to join the study and the husband's were not happy with it. The other reason was that some husband's did not want "wet sex" as such they did not accept the use of the gel. A reporter in one of the Malawi news



papers indicated that women are at higher risk of contracting HIV because decision on how and when to have sex are generally made by men. This is associated with the power and economic imbalance between men and women that has predisposed women to have no chance to deny or negotiate their partners' decision. This report further indicated that women fear that support can be frozen or their partner will marry another woman if they do not do what their partners want them to do(53). This has predisposed a lot of women to risk of contracting HIV.

#### **3.2.2.2 Women as care givers**

Since childhood girls are trained to take care of the family members. As such caring was considered a role for women only. With the coming of HIV and AIDS there is an increase in demand for care such that women are not able to cope with the demand. In response to this, National Association of People Living with HIV and AIDS in Malawi introduced home based care groups that involve male participation in most of the districts in Malawi(54). Male involvement in the caring role was also observed at the clinic where some men brought their wives to receive treatment. The way they handled the wives at the clinic setting showed that they could be doing the same at home. With these few positive changes it does not mean that the situation has changed completely, a big burden of care is still with women since they devote most of their time to care for the sick as such increasing their economic dependence on men(55). There is evidence that some men are still stuck in their culturally ascribed roles. This was shown by narration of some women who participated in the study. The women narrated that the moment their husbands saw that they were getting sick so often they told them to go to their home villages to be looked after by their mothers and aunts. Narrations from key informants indicated that most often when women get sick, they do not receive care from their partners in the same way they do for them. They have related this to culture that men are not trained to be care givers as such it becomes difficult for them to care for their partners when they get sick.

However, concerns were raised from some of the men that the researcher met when she visited two HIV and AIDS support groups during data collection. These men complained that they are being mistreated by their wives who are telling children that their father is sick because of their immoral ways. One of these men narrated that he had problems at home with his wife who used to abuse him

verbally because of his HIV status. If we can refer to the told story this is one of the good examples of men who have faced such challenges.

Lindgren (2005) in a study that looked into Socio cultural and barriers of HIV in Malawian women indicated that women needs economic empowerment and higher education to be liberated from the negative impact of the gender imbalances(48).

Currently, there are some organizations that are empowering women to do some small scale businesses and the government is encouraging girls to acquire high education so that they can be able to make decisions on issues that concern their lives.

### **3.2.3 Religion and religious institutions**

Religion is considered as an important part of most Malawians. According to official statistics, majority of Malawians which constitutes about 55% are Protestants, followed by 20% Catholics, another 20% Muslims and 5% of the remaining sum are affiliated with other traditional religious beliefs (56). Generally male dominates leadership positions in the religious institutions except in a few evangelical Malawian churches that have opened doors for women to take leadership roles(55).

Ntabeni (2005) states that, to most Africans religion gives a meaning to their existence, substantiates and explains their role in the society. In-case of illness it provides hope for healing to the adherents and it is also regarded as means of social control(57). This is similar case with religion in Malawi, reports have shown that religious institutions in Malawi teach members moral values to which they are expected to abide to(58;59). The reports have further indicated that most Protestants and Catholic churches focus on behaviours that includes; fidelity and abstinence as a way of living a righteous life(55;58;59). As such every member is held responsible for keeping the moral values that are taught by their different denomination.

In most religious circles, religious leaders are trusted by their members who in cases of problems find it more convenient to confide in their leaders. This is consistent with what some participants of this study reported of the support and encouragement that they had found from their religious leaders. The religious leaders are known for giving counsel and offer prayers to their members' in need.

With the coming of HIV and AIDS epidemic, reports have indicated that some religious institutions have responded negatively and unwilling to engage in HIV and AIDS related issues. These reports have claimed that the religious leaders thought that engaging in HIV and AIDS issues could imply dilution of moral standards because of the association of HIV infection with promiscuity(58;60). Some religious institutions have been reported of condemning people living with HIV and AIDS as sinners, as well as condemning use of condoms as a means to fight the epidemic(44;61;62). Because of such attitudes, it has been reported that religious institutions took a lot of time to learn the facts about HIV and AIDS as such their influence on curbing the epidemic had been very minimal in the beginning(55).

Lately most of the religious institutions have engaged themselves into the fight against the epidemic. Some reports have shown that religious institutions have now taken a central and positive role in the fight against the epidemic. This has been evidenced by establishment of interfaith based organization secretariat that oversees the HIV and AIDS related activities in religious institutions. The reports have further indicated that institutions are now giving material support, care to orphans, PLWHAs through home-based care groups and teaching church congregants about HIV and AIDS and the importance of VCT(59;61;63-65).

An interview with two key informants who heads different religious institutions (Islam and Christianity) highlighted on how these home-based care programs are run. They also indicated on problems that they encountered to meet the demands in the communities that they were serving. These two leaders further reported that their institutions are teaching religious leaders about HIV and AIDS to help reduce stigma and discrimination in the Church circles. However, reports have shown that though church leaders are being empowered with this knowledge there are others who still use condemnation languages. While others are preaching love for people living with HIV and AIDS, and encouraging members to go for VCT. Others have not yet taken it as their concern they still use stigmatizing and discriminatory languages against the PLWHAs. As indicated by some church ministers from two different denomination in the following quotes; *“time has come for the church to seriously think of how ill-behaved and stubborn people who fail to take heed of the church’s stand-*

*abstinence can as well be saved from the epidemic(59)*”(from Malawi weekly nation newspaper 2-3 Jul 05).

*“(...) those who do not abstain or remain faithful to their partners and have contracted the virus should not blame God since everyone has a free will to choose what they want to do(58).”*(from midweek chronicle Vol. 12 no 562 4-7 Aug 05)

This might display the picture that some church leaders have on people who have HIV infection. That HIV is infection for people who are not faithful to their partners. This shows that though the reports indicates that the religious institutions have taken a positive role in the fight, there are some institutions and their leadership that have not yet embraced the challenge in the way they have been called to act. As such this creates the “them and us” attitude that leads to stigmatization of people living with HIV and AIDS.

Rankin (2005) in a study that looked at familial, cultural and religious influences on Malawian women that contribute to HIV and AIDS indicated that some religious leaders have not yet responded sufficiently to help stem the epidemic, instead they are preaching repentance to PLWHAs and criticizing condoms(55). This indicates that in some religious institution HIV infected individuals are considered as sinners.

### **3.2.4 Sex and Sexuality**

Hetero-sexual contact is the only sexual relationship that is socially and culturally accepted in the Malawian society. Traditionally sex has many dimensions in Malawi, it is a means of procreation, an emotional expression of love, friendship and a means of earning a living (55;66). In friendship sex is expressed in the same way just like the material gift would do. Of all these, affectionate sex that is in the expression of love and procreation are linked to individual character and societal moral attributes. These attributes are determined by religious and cultural morality(66). This section gives an overview of sex and sexuality issues and how they are understood and practiced in the Malawian culture.

#### **3.2.4.1 Sexuality and religion**

In the religious context sex outside marriage is considered as a sin. In the cultural context issues related to sex are considered as taboo and therefore they are not discussed in public(67;68). This belief was reinforced by Dr H. Kamuzu Banda, first president of the republic of Malawi who also believed in upholding Christian values. He condemned decadence and vulgar language common in the western world. He believed this had a negative influence on the youth of Malawi (55;69).

In religious circles teachings on sexual issues are emphasized on abstinence in the youth and faithfulness to married partners. A report in one of the Malawi news papers indicated that parents give similar teachings to their children. This is in agreement with another report that has indicated that parents do not talk in an explicit manner about sexuality issues with their children because it is considered a taboo (55;68). This responsibility is most often given to other elders such as Aunts, Uncles and grandparents who most often give inadequate information(70). Nkosi in one of the Malawi newspapers indicated that the implicit teachings of sexual issues have not helped much in assisting the youths to understanding themselves sexually(67). Horne (2001) claimed that secrecy and denial that surrounds sex and the education about it has resulted into public support of abstinence and the private denial of it (68). This has been confirmed with the rising figures of HIV positive population among the youths and adults in the reproductive age group.

#### **3.2.4.2 Sexuality HIV/AIDS and Culture**

With the coming of HIV and AIDS it was a challenge to the Malawi nation with a culture and religion that leads the society to basically being silent on sex related issues(67). This made public health teachings difficult to the health workers as teachers and the public as recipients of the messages. When ever public statements about HIV and AIDS were made speakers used sexual metaphors such as “eating”<sup>3</sup> (*kudya*) to input normative information to the targeted groups(69). The use of such metaphors has also been identified in men and women’s explicit conversations about sexuality issues(71).

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<sup>3</sup> Eating is a metaphor which means having sex.

In the beginning public health teachings focused on equating HIV to death as well as promiscuity. Lately, focus has changed to unprotected sex as the mode of transmission rather than promiscuity. In regard to this, people are encouraged to abstain from premarital and extramarital sexual relationship; those who are married are being encouraged to be faithful to their partners. At the end of these messages people are told to use condoms as a protective measure from contracting HIV if they are not able to abstain. This gives a picture that those who use condoms are people who are weak, who can not manage to control their sexual desires. On the other hand if one just mention of the condoms or seen with condoms people think you are promiscuous, you use condoms because you can not stick to one partner. This might lead to stigmatization of People living with HIV and AIDS because the teachings create a judgmental attitude in how the public view and understand HIV and AIDS transmission. Despite the changes that have been made in the health teachings oral discourses have shown that a lot of people are still holding on to the messages that were preached in the beginning. People are still relating HIV to death, as well as HIV and promiscuity.

Over time HIV and AIDS has brought a difference on how Malawians are handling issues related to sexuality. Currently there is a lot of information on, HIV and AIDS education that includes: care and prevention in the form of sports for youths, radio and television programs, billboards along the roads, posters in the clinics, gender and HIV, advertisement of condoms and creation of youth HIV and AIDS clubs in schools. All these messages are meant to help with behaviour change and equip people with “life skills” on HIV prevention and living positively with the virus. In addition there are other radio programs like “let’s talk” and “breaking the silence,” these are programs that encourage families and the public at large to discuss explicitly about sexuality issues and HIV and AIDS “if we are to win the war against this epidemic.” From the oral discourses it seems like some members of the society are not comfortable with these discussions and they are resisting the efforts to be more open. One of the chiefs complained in one of the Malawi news papers that sexuality teachings on the radio are contributing to immorality among the youth. He narrated that the explicit way of talking about sexuality issues have acted as an eye opener to the youths as such it is promoting promiscuous behaviours (72).

The advertisement and promotion on condoms has met with conflicting views on sexual behaviour from the society. While others think use of condoms will help save lives, some are saying no to the use

of condoms. Some of those who do not agree give reasons that promotion of condom use will lead to promiscuity and unfaithfulness. Others are saying that condoms signify sin as such they can not stand people who walk about with condoms in their pocket (73). This means that to others carrying condoms is a sign of loose sexual behaviour. In a study that looked at spousal communication about the risk of contracting HIV and AIDS in rural Malawi indicated that discussions about prevention within marriages focussed on fidelity rather than safer sex, condoms are often associated with extra-marital relationships (51). Such type of behaviour has also been reported in Kenya and Tanzania(74).

#### **3.2.4.3 Sexuality practices and gender**

Though it is indicated that extramarital and premarital sex are not accepted by culture and religion in Malawi there is discrepancy in these claims and the actual practice. The practice has shown that men do have extra-marital affairs. Most often this is associated with high economic status. Chirwa (1997) indicated that men who have material resources engage in multi-partnered sexual relationship as a symbol of economic and social success(66). But in women such kind of behaviours are not accepted and they are punishable by culture and religion as indicated by some key informants who participated in the study. The implications that this kind of practice has on gender has been highlighted in the findings chapter.

## **Section: D**

### **FINDINGS AND DISCUSSIONS**

The aim of the study was to explore the experiences of people living with HIV and AIDS in the Malawian urban setting and the scope was limited to HIV and AIDS related stigma. The core participants were enrolled from one of the specialized HIV and AIDS clinic in Lilongwe city. In addition, people holding key positions that gave them knowledge in the topic understudy were also recruited from different work places. To achieve the study's main aim, data was generated through: [1] clinic observations, [2] analysis of public, semi public and clinical discourses, and [3] interviews with key informants and PLWHAs as indicated in the methodology chapter.

The findings of the study have been divided into two sections; the first section gives an overview of the clinic setting, HIV testing process and its possible implications on VCT clients. The second and last section is the presentation of findings in four themes that have been presented in four chapters. These include; [1] HIV, AIDS and culture, [2] the consequences of living with HIV and AIDS [3] management of reputation in the community and [4] the beginning of new life.



## **Chapter 4.0: HIV Counselling and Testing Process (clinic setting and operations)**

One of the specific objectives of this study was to explore how stigma is expressed at different levels. That included; health care systems, family level, community level, work place and religious institutions. This section gives an overview of the clinic environment and operations that may have had an impact on the lives of people who receive HIV diagnosis. A description of the clinic setting, how one enters the clinic premises, the process of testing, giving and receiving of the test results has been given below. Schneider and Adam (1992) claimed that there is no social organization without an impact on the lives of people infected with HIV(75). Therefore, the description of the testing process has been considered important in this report because of two reasons; [1] this is the time that participants are faced with a challenge of receiving HIV diagnosis and [2] it is also a time that participants are counselled on how to cope with their diagnosis. The researcher will give an account from the observations that she had conducted at the clinic during her field work.

### **4.1 Clinic environment**

People came to the clinic for different reasons: that included HIV and AIDS primary care<sup>4</sup>, monthly refill of ART and HIV testing. Among those who came for testing, some were referred from other hospitals because of ill health. Others came on their own and reported that they had wanted to know their status.

At the entrance of the clinic gate, there was a sign post that directed people to the services rendered at Lighthouse clinic. These included; voluntary counselling and rapid HIV testing, clinical care for HIV positive clients, antiretroviral therapy and day care wards.

As soon as one entered at the main gate, there is a small house for watchmen. These watchmen gave directions to new clients depending on the reasons for their visits. There were two directions; one leading to the right where clinical services were offered. The other direction to the left, led to voluntary counselling and testing services.

Since its opening up to the time of field work, it was a must that one has to show HIV positive test results to receive clinical services, that includes primary HIV and AIDS care or ART. If one reports

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<sup>4</sup> Primary care is the treatment that PLWHAs get for opportunistic infections before the initiation of ARVs

without proof of having been tested HIV positive he is offered the services but is referred for HIV testing. This is a requirement if there is need for follow up care or the patient is referred to the main hospital for continuation of treatment.

At the time of field work the lawn around the clinic was green and beautiful. Patients were sitting on the veranda, in a queue waiting for their turns to be attended to. Some guardians were sitting under the trees waiting for their patients.

#### **4.2 VCT reception**

The VCT centre operates from Monday through Friday, the services starts at 8.30 and close at 16.00 hours. This centre has four counselling rooms and one office for the VCT coordinator. At the moment people entered the VCT centre, they are welcomed by a receptionist who gave them a number. They waited on a queue leading to counselling rooms. Most often, the queue was not long, just about 3 to 8 people per time.

There were a number of HIV and AIDS posters on the walls at the reception, these posters were conveying information on prevention of HIV transmission and promotion of care. The messages on the posters were for different target populations. These included the youth, women, men and families.

The posters carried information on; abstinence and use of condoms, encouraging women not to be enticed by money to avoid infection, the other poster discouraging men from enticing women with their money.

These posters carried different pictures; the one with abstinence message carried a picture of a young man standing and pointing at his head. The poster for women had a picture of a man with a briefcase on his right hand standing besides his car inviting a woman. The picture indicated that the woman ignored the call by turning her face away from the direction where this man was standing. This poster carried a message that women should not be enticed with money but they should be faithful to their partners. The poster for men carried a picture of men in a bar with sexual workers. One of these men

embraced a sexual worker. The message was that men should not allow money to control their sexuality which in the end can lead them to death.

On the other end there was a television where people were watching HIV and AIDS programs. The programs included; functions that took place in Malawi at a particular time such as candle lighting memorial (a ceremony that is conducted in remembrance of people who died of AIDS) music from the Malawi health education band on HIV, AIDS and care, drama by AIDS support organizations drama groups.

As people waited for their turns to enter the counselling sessions they seemed not to be comfortable with the waiting time. Others looked stressed; those who came with their guardians shared their fears with them about the testing process and the outcome. After every session the counsellors would come out with their beautiful smiles to call the next person. This seemed to be challenging to the clients on the queue as most of their faces showed that they were filled up with fear of what would come out of the testing process. I could guess the reasons why some people could not come for their HIV results previously before the rapid testing was introduced.

### **4.3 Testing process**

Though the environment was quiet cool with beautiful lawn, flowers and beautiful trees that provided shade to the guardians, the hearts of many who were coming to this place were not as peaceful as this environment. The news that this environment brought to people who came for testing, disturbed lives of many. If we are to look for a meaning of the name of the clinic itself “Lighthouse” one can interpret the kind of light that this house gives to people. To those coming for ARVs it instils hope, what about those receiving HIV diagnosis? does it carry same meaning?

I will relate an experience of an HIV testing with a young man who had just graduated from the University who came to the clinic for HIV testing. This was one of the cases that I had observed in the counselling sessions during field work. When this young man had entered the counselling room he was greeted by the counsellor who later asked him what made him to come for testing. In response, he said that he wanted to know about his status. He was counselled following the country’s standard

counselling scripts in preparation for the testing (refer to appendix 6). Following this pre-test counselling the counsellor asked if he was ready for the test. He consented to take the test. Blood was drawn and rapid testing was conducted. Whilst waiting for the results the counsellor asked the client to wait outside the counselling room and she used the time to write notes on the counselling process.

When the results were ready the counsellor called in the client and asked if he was ready to receive his results and he accepted. The counsellor gave the results. At hearing that he had tested HIV positive, he was disturbed. He mentioned how life will be like for him with the diagnosis, his fiancée in college with whom he had made plans to get married as soon as she finishes with her studies, he complained about his education that it will not benefit him anything because of his HIV positive test result.

All this narration came when the counsellor asked what reactive results meant to him. The counsellor took her time to explain slowly the nature of HIV and disease progression. She tried to normalize the situation according to the training that is given to counsellors. She told him that he is not the first person to receive such kind of results as it happens to many people and that being HIV positive does not mean that one can never get married, she also mentioned that having HIV does not mean that it is the end of life. He seemed to have understood what the counsellor explained and he was taught on how he could live positively with the virus since he looked healthy and energetic. He was also advised to go for CD4 cell count<sup>5</sup>, just to have a check of his immunity levels. A week after this session, the researcher met this young man in the hall way at the main hospital. He explained that he had gone for CD4 count and it was below 200 therefore he had to start taking ARVs. He was visibly sad at the time he was explaining of his CD4 results.

During the time that this young man received his HIV test results, the counsellor tried to give information that could help normalize the situation. She had explained the different modes of transmission which were meant to help the client understand the condition. However, the information that was given during the counselling session was different from the messages that were portrayed by the posters at the reception which focused on sexual transmission only. The messages were communicating on the importance of decision making. The interpretation that I gathered from the

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<sup>5</sup> CD4 cells are part of the white blood cells that help fight body infection.

poster that was for the youth was that they should make use of their brains to make decisions on abstinence or using condoms and not just following what their peers do. To men and women the messages were that they should make good decisions not to put their focus on money that can lead to indulging into promiscuous behaviours.

It is worth noting that the message that was given by the counsellor and the posters were contradictory to each other. The counsellor tried to generalize the problem to help the client not to have feelings of self blame. Looking at the posters it meant that those who test HIV positive did not make proper decisions for their lives that is why they contracted the virus. This could lead to feelings of self blame to the people infected as well as internalization of stigma. These messages can as well lead to public's imputation of blame on the people infected. Going back to this young man's situation, the diagnosis seemed to have interrupted his life course. As a young man who had just finished his studies, he had a number of expectations that he had to fulfil as well as accomplish the society's expectations of him as it is expected of each and every youth of his age. Receiving HIV diagnosis had apparently put his life out of balance. His narrations at the time he had received his HIV diagnosis indicated that to him this diagnosis meant loss of his future. With this diagnosis he thought he could not live to enjoy the benefits of his degree, he could not live according to societal expectations of him. Among other things that included; getting married and having children since people living with HIV are given options to choose whether to have children or not in regard to the problems that may come with the reproductive process.

His narration has shown that he started viewing himself as a different person from other people of his age and gender immediately at the time he had received this diagnosis. Such kind of narrations gave a glimpse of the social orders in this society. Therefore, the next section highlights on the meanings that people attach to HIV and AIDS in the Malawian society. I will do so by discussing meanings centred on the four themes that have been identified as of great significance in this analysis. The discussion will draw data from core and key informants interviews, notes from fieldwork, data from reviewed documents and analysis of discourses in general.

## **Chapter 5.0: HIV, AIDS and Culture**

### **5.1 Reaction to HIV/AIDS diagnosis**

One of the specific objectives that this study had to answer was to explore meaning of HIV/AIDS stigma in Malawian urban setting. To achieve this objective, the researcher asked the core participants to explain their immediate reaction at the time they had received their HIV diagnosis. In response, their narrations showed a wide range of experiences that included the following; helplessness, worry, anxiety, disappointments, disbelief, sweating a lot, loss of hope and feelings of hopelessness. However, there were also a few responses that indicated that they were neither worried nor shocked at the time they had received their HIV diagnosis.

When participants were asked to explain the reasons for their reactions, among other reasons they explained that they did not expect to receive such results because they had been faithful to their partners. Those who had claimed that they were not worried gave reasons that they had expected these results because of their previous promiscuous behaviours. The different reasons that the participants narrated between those who had claimed that they were not worried and those who had claimed that they were worried raised further the researcher's curiosity to learn more about the meaning of HIV to the people infected and what they thought HIV diagnosis meant to others.

The core participants were also asked to explain what they thought having HIV meant to them at the time they tested and to other people in their community, either their friends or relatives and others. Though these participants differed on how they reacted to their HIV diagnosis almost all of them shared the view that they had thought death was imminent and inevitable. In response to what they thought having HIV meant to other people, they all mentioned that most often people in their families or neighbourhood think that individuals diagnosed with the virus had been careless with their lives. They also stated that others think that the individuals diagnosed with the virus can not live long. Further narration indicated that "careless with life" meant that the individuals infected must have had multiple sexual partners.

Similar questions were asked during the interviews with the key informants. In response they gave scientific meaning of what having HIV meant to them. When they were asked what they thought could

be the meaning of HIV to others, they gave similar responses to what the core participants gave on this question. Similar explanations were also observed from public discourses.

The narrations from the interviews and data from discourses indicated that the information that people have on HIV and AIDS dates back to the first HIV teachings at the beginning of HIV and AIDS epidemic in Malawi. As indicated in the context chapter the first HIV teachings emphasized on the association of HIV infection with promiscuous behaviour. This led to creation of categories of people who were labelled as potential candidates for this infection. These were people such as; women bar attendants and truck drivers because of the nature of their work. Schiller et al (1994) claimed that identification of risk groups that are considered as holding unique cultural characteristics represent AIDS as a disease that exist in distant and separate populations(76). This is consistent with the reasons that participants reported of not expecting an HIV positive test results because they had never been “careless with their lives”. Similar reactions to HIV diagnosis were also reported in a phenomenological study that looked into the stressors of living with HIV in Taiwan(77).

Though some participants indicated that they had never been “at risk of contracting the virus” their narration showed that they had changed sexual partners at some points in their life course as stated in the quote below;

In the past when I heard about the virus being present in our country I felt that we cannot be infected with the virus. I was thinking that the virus can only be found in those who look sick and not the way I am looking. It's really a surprise to see that I am now the one infected with the virus unlike the people whom I felt that they can easily be infected. I had a lot of questions on how I had contracted the virus. Of course I have gone out with some women but not to the extent of contracting the virus, since the disease has come for people and that there are different ways of contracting the virus let it be like that.

I used to have one girlfriend at a time. If we have problems I could go for another woman not having multiple partners at once (*a 29 year old male PLWHA married with one child*)

This quote points to a number of factors that may have led to denial of HIV positive test result in the stated case and other similar cases. In the first place he narrated that: 1) he felt that he could not be infected, 2) virus can only be found in those who look sick, 3) he had gone out with women but not to the extent of contracting the virus, he was having one partner after another.

In such kind of cases, this may indicate that their interpretation of risk was different from the public health teachings point of view. Douglas and Calves (1990) in their cultural theory of contagion in relation to AIDS claimed that scientific knowledge does not diffuse smoothly in different sects of the society. This is so because of the value that members accord to its pronouncements. Some members in the society may take science as something that does not speak with one voice and that at times it has uncertainties that underlie its pronouncements. Such that some people consider their bodies as immune while others consider their own bodies as vulnerable to infection. There is a possibility that the stated case considered himself immune to the infection as compared to others whom he referred to as sickly people (78).

However, there is also a possibility that the three points drawn from the quote might indicate that; he had a special group of people whom he thought could be the potential candidates for this infection. This may be related to the first HIV public health teachings.

The second point could relate to two things; firstly he was looking at his health and secondly the health of the sexual partners that he used to have. Kaler (2003) in a study that he looked into AIDS talk in everyday life in Malawi found that some men use biographical characteristics to estimate whether a particular partner is likely to be HIV positive rather than practising safe sex(40). Therefore such type of behaviours could be related to this case.

The last point may highlight a problem in how health messages are conveyed to the targeted groups such that the audience have problems to understand what the message is all about. It might also mean that promiscuity to him was not having one sexual partner at a time but having multiple sexual partners at the same time. Adam (1992) notes that identification of at risk groups of infection may create categories in which people do not recognize themselves as being at risk. This in some circumstances can lead to denial of personal risk like in the stated case. It was also indicated by Schiller et al (1994) that the approach of identifying risk groups hinders efforts to prevention and education of the public about the potential impact of the epidemic on the entire society(76). The above stated case may be an indication of such instances. In the same vein, there were other participants who reported of having ignored HIV and AIDS education broadcasted on the radio before they received HIV diagnosis. They



reported that they did not consider the information as relevant to them since they had been faithful to their partners.

As alluded to earlier on in the context chapter, promiscuity is not accepted by Malawian culture and religion. Premarital sex is also reported to be condemned by culture and religion. Therefore, when one receives HIV diagnosis it shows that one did not abide to the cultural or religious norms. It was made clear from the interviews with both PLWHAs and key informants that the diagnosis is taken to explain a character of a person, in relation to cultural and religious moral issues. As one PLWHA puts it in the statement below

My life in the past I was not careless or having many sexual partners and I was wondering where I contracted the virus because I was very faithful to my wife so I was shocked. I was praying a lot and people looked at me as someone with good manners. (*a30 years male PLWHA separated*)

The statement above indicates that people who are believed to be religious and faithful to their partners are believed to be safe from contracting the virus. Therefore, receiving of HIV diagnosis in this category might indicate that you have been cheating people that you are religious. This might lead to experiences of felt and enacted stigma.

Almost all the participants shared the view that AIDS is a shameful disease because of its association with promiscuous behaviour. Such that PLWHAs narrated having experienced feelings of shame because of the infection as some of them repeatedly referred to AIDS as a shameful disease. Goffman (1963) states that “shame becomes a central possibility, arising from the individual’s perception of one of his own attributes as being a discrediting thing to possess and one he can readily see himself as not possessing”(19). Being part of the society there might be a possibility that participants shared the same meanings and beliefs that are attached to HIV diagnosis and the categories of behaviours that are considered risky for HIV transmission that might have led to the internalization of shame.

According to the narrations shared by the participants, it seems that the meaning that people attach to HIV diagnosis is closely related to the circumstances that lead one to contract the Virus. This therefore, relates to the people’s understanding of biomedical definitions of this infection as well as religious

or/and social cultural insights into the nature and moral significance of the relationships in which infection occurs.

Almost all the participants claimed that the link that was made between HIV and the above stated factors led to maltreatment of people living with HIV. The narration from both interviews and data from the discourses indicated that public view people living with HIV as outsiders, people who have failed to live according to either cultural or religious norms. A key informant from media summarized it in the claim that he made when he was asked to share what he thought could be the reasons why people treat PLWHAs in an in-human way.

I can say that these things are really there. Aah I can say that when we look at our culture we believe that when we tell the child not to do something, the child will automatically stop. Our culture has got some dos and don'ts and we very much emphasize on the don'ts. When our culture say that don't do this when you go ahead to do it they will come back to you to say that we told you not to do that and you went ahead to do it. Since we always say that the chief mode of HIV transmission is through sexual intercourse, and parents will always say that boys or girls are dangerous and when you have contracted the virus, the parents will always refer back that we told you not to do that but did not want to listen to us. So this is now the end result. They do apply these things to HIV and AIDS forgetting that you may have contracted the virus through razor blades, un-sterilized injections or possibly your partner was unfaithful. We are spoiled by our culture. The other issue is that some people are not able to come forward in the church because there is a lot of stigma and discrimination in the churches. People in the church believe and conclude that every person who is HIV positive contracted the virus through sexual intercourse with different partners. They forget that you may have contracted the virus through other modes of transmission. And contracting the virus through sexual intercourse is not a guarantee to condemn such a person. We do have such an attitude where we are condemning those PLWHA. Others believe that HIV and AIDS is a punishment from God. One of our diarists said that when I told the pastor at Church, the Pastor said that we have been telling you that this is punishment from God. Where were you all these days? We have been telling you to be coming to the church to pray with us but you were not interested and you were enjoying your life. Now you have contracted the virus, which is punishment from God. ( a male *Key info from the media*)

The above statement may indicate that people contract the virus because of indulging into practices that are considered deviant by culture and religion. Though there are many ways of HIV transmission such as razor blades, mother to child transmission these are considered less. Interviews with both key informants and core participants including data from the discourses indicated that majority of HIV and AIDS cases are lumped together as people who have been “careless” with their lives with only a few cases that are referred to as “innocent victims” such as children. All the participants claimed that it is in this view that people living with HIV and AIDS are stigmatized and discriminated against in

different settings. Alonzo (1995) claimed that those that are considered as “innocent victims” such as children are treated less harshly(38). Jones et al (1984) indicated that when an individual is believed to be responsible for the origin of his “mark” he is more likely to be treated unfavourably and in others who are believed not to be responsible for the mark may receive permissive treatment.(79). However, this does not apply to all cases of children who receive HIV diagnosis. Narrations from other PLWHAs and key informants showed that some HIV and AIDS orphaned children were mistreated by their foster parents because of their HIV status. It was mentioned in one of the key informant’s interviews that other orphaned children who received HIV diagnosis were relocated from their foster parents in town to go and stay with their grand parents in the village. The key informants speculated that this could be attributed to fear that they could infect their children.

## **5.2 HIV/AIDS, sexuality and gender**

As indicated in the context chapter, Public health teachings encourage faithfulness to one’s partner, abstinence and safe sex. As it was also indicated by the posters at the clinic as well as highlighted in the clinic health education sessions, this was used as one of the reasons for self imposed blame among some of the PLWHAs. These were among those who had claimed that they were not worried with their HIV diagnosis. Their narrations indicated some sort of self imposed blame for not taking heed to the messages in the public health teachings.

It’s because in those years we knew that the chief mode of HIV transmission is through unprotected sex with different people, deliberately is coming in because I know that I had more money then I ended up having sex with different people. I was really aware that I would end up contracting the virus because at one other time I had sexually transmitted infection but I did not change my behaviour, I still continued going out with different women.(a 34 year male PLWHA, married with 2 children).

This statement points to two factors 1) factors that lead to promiscuous behaviours that are reported to be common in men and 2) self blame for contracting the virus because of making bad choices. The narration in the above quote indicates that money was a factor that led to promiscuous behaviour which at the end predisposed him to contracting the virus. Chirwa (1997) claimed that multi-partnered sex in Malawi is considered as a symbol of economic and social success (66). Therefore, this may indicate that though culture does not accept promiscuous behaviour, such practices still exist in men who have the material resources. Lindgren (2005) in a study that focussed on social cultural factors and barriers to prevention of HIV infection among Malawian women, confirmed the ambiguity that exist in men’s

multi-partnered sexuality in Malawi. He indicated that though multi-partnered sexuality is condemned in the Malawian culture and religion, it is condoned in certain instances (48). Therefore, men's sexuality practices in Malawi fit with these claims.

The second point may indicate that the knowledge on mode of transmission has been given and people have the knowledge, however, they make wrong choices. Though some men concluded it in this sense, interviews with the female PLWHAs showed that men and women do not have equal opportunities of making such choices. Their narration indicated that culture does not permit women to make decisions regarding sexuality issues. Similar explanations were also shared by some of the key informants. However, it was noted that though this was the case women were blamed for their infection.

Ah, there are a lot of things which happen because we were able to interview some people on what they feel are the reasons for these things to happen, like these things being done by your own parents. Most of them give different responses like some girls would say that my parents were telling me that I should not put on trousers because that will attract men. And you will contract the virus from these men. If you become infected, never come to my house again. Later you discover that you are infected they just tell you to move to the boys' quarter (*key info NAPHAM*).

The statement above indicates layers of blame that are imposed on girls and women for their infection. This statement may mean that it is the women's fault by dressing in a way that is regarded as inappropriate. That may arouse men's sexual desires and lead to their infection. Second blame is the contractions of the infection itself that may indicate lose moral character. Therefore this implied that women are there to help control men's sexual desires that can be "aroused so easily" by women's "inappropriate" dressing. This might also indicate that people sympathize with men for their infection because of their uncontrolled sexual desires.

It was also indicated in some core participants' narration that some women were blamed for their partner's infection;

We went to his home village for burial ceremony and I only spent one night. The following day I was told to pack up my things and go back home because I was the one who killed their son and they had nothing to do with me. They felt I am the one who transmitted the virus to him. It was very pathetic to me to hear that I am the one who transmitted the virus to him after all I was just a mere house wife just staying at home. My husband was a businessman who could spend some days out and I didn't know what he was doing out there. He was selling second hand clothes. We were also having some family problems and they were not interested

in assisting us sorting out those problems (*A 37 year female PLWHA, widow and a mother of 3*)

This narration also indicated the association of mobility and high chances of contracting the virus. This could be related to the categorization of higher risk groups as it was indicated in the first public health teachings.

Though women PLWHAs attributed their infection to their partners' high risk sexual behaviours, most often they were the ones receiving the blame for their partner's infection. This was so, despite the extended family members' knowledge that their sick relative was having extramarital affairs. One of the key informants indicated the probable reasons to these inappropriate behaviours;

In our cultural setting, men don't engage in adultery but women do. A woman who is diagnosed with HIV and AIDS is automatically labelled as an adulteress and people think that she was engaged in an act of infidelity. Even the community/society will give a man a go ahead to divorce the wife. Even in a church setting, if one of the two between a man and a woman are caught in an act of adultery, it is very easy to excommunicate a woman than a man. Its not that the church accepts but culture looks at a woman as more adulterous than a man. Many programs and teachings on HIV and AIDS are targeting women. For example there are many programs for commercial sex workers. These commercial sex workers are mainly women but sexual contact involves two people men and women so why only women? But you will never see program that targets men, no. This is so because the men involved are financially empowered and make decision than the woman they go about with. So HIV and AIDS is greatly affected with gender in equality and gender imbalance because of resource and perception of women in society (*a male key info from EAM*<sup>6</sup>)

The imputation of blame on women for their partners' infection was also depicted in the local secular Malawian music. Most of the local songs on HIV and AIDS portray the picture of women in the epidemic as the sources of HIV transmission. One of the PLWHAs expressed concern over some secular local songs that she reported of discrediting people living with HIV. This was at a launching of the National program and plan of action for women, girls and HIV where the researcher was in attendance. Two songs were given as examples; *akunenepa nako kachilombo* (they are getting fat with the virus). This song talks about women that people should not be taken by being fat. Some female PLWHAs are fat because of contraceptives. The other song, *akuvularira mkati* (they are being wounded from inside) tells men that they should not be taken by good looks, fairness of skin because these days people are being wounded from inside. These are just a few examples of the many songs

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<sup>6</sup> Evangelical Association of Malawi

that give an impression that the infection is in women. To the researcher's surprise some of these songs feature women when they are being played on the local television station. The women play a role of a fat woman with light skin. This might be one of the reasons that reinforce the imposition of the picture that the public has on c women in relation to HIV infection.

These songs are meant to convey messages to men that they should take care when selecting women for sexual partners. The reasons why women are always blamed for this infection are not clear as indicated in the above quote that even if it is that women sell sex, the transaction of this business is between both women and men. Rankin (2005) and Alubo (2002) indicated that in African societies women are frequently stigmatized as vectors of HIV transmission despite the overwhelming evidence of the true picture of the situation(80;81). This unequal imputation of blame on men and women was also claimed by other studies that have looked into HIV and AIDS related stigma and discrimination in other contexts (80;82-85).

### **5.3 HIV/AIDS stigmatizing terms**

Narrations from both interviews and the analysis of public discourses indicated that lack of clear and concise local meaning of HIV infection and AIDS has led to interpretation of HIV and AIDS into different terms. The data from different sources also indicated that this has led to creation of different kinds of names and use of derogatory terms that are stigmatizing to the individuals living with HIV and AIDS. One of the Malawian news papers that the researcher came across during her field work indicated that there were many slang terms in vernacular and in English referring to HIV and AIDS. This news paper article indicated that some of the terms are quite amusing, but nearly all of them are "disrespectful and stigmatizing". The author claimed that the high levels of stigma, fear, and negativity that surround HIV and AIDS in Malawi and in the region are fuelled intentionally and sometimes without knowledge by bad, negative HIV and AIDS languages.<sup>7</sup> Some of these terms were shared by the participants during the interviews, some were noted in some of the news papers, informal conversations and in the counselling session that took place at the clinic during the field work.

One key informant indicated that the basis of these terms is on the meanings attached to the infection:

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<sup>7</sup> Quoted from Sunday times, august 21 2005.

... I will take practical experience that I have seen. I feel in the first place people have these views because they lack knowledge on the meaning of HIV and AIDS. Because in our local language we say HIV is (*Kachilombo*)<sup>8</sup>. This gives bad impression to the people. So people feel that if HIV is *Kachilombo* then the person who has HIV is an animal as well (*Chilombonso*). So since this person has the virus in his body they start discriminating him (*a male key informant from the media*)

The narration above indicated that the literal translation of HIV infection brought with it some fears into the Malawian society.

Some of the terms used included: names that were given to people living with HIV or AIDS such as; *wakachilombo* (with a small animal), a jacket on a hanger, skeleton, *a paulendo* (those who are on a journey) and *maliro oyenda* (moving corpses). Most often the term *wakachilombo* overrides the identities that the person had before people knew about his/her HIV sero status. The last two names *a paulendo* and *maliro oyenda* relates to the fatalistic views that people had on HIV and AIDS. As highlighted in the context chapter the association of HIV and death in the public health teachings gave people the impression that once one is diagnosed with HIV meant that death was imminent. One of the PLWHAs narrated in the quote below.

My life since... my life since... since I knew that I was found with HIV and AIDS, I was worried that may be I will leave my children... my children will be Orphans, this will be my death (*a 38 years female PLWHA separated and a mother of 3*).

The last two names indicate the inevitability of death associated with HIV and AIDS cases.

The other terms were taken note of in counselling training that drew participants from all the 28 districts in Malawi. The researcher attended a presentation on the languages of HIV and AIDS. Participants came up with a list of different terms that are used when someone receives an HIV positive diagnosis. That included; *Njoka ya muluma* (has been bitten by a snake), *wadya bonasi* (has received a bonus), *waponda bomu* (has stepped on a bomb), *wakumana nazo* (has met it), *wadya zake* (has eaten his), *Wavisanga*<sup>9</sup> (has found it), *kadalowa* (it is in). These expressions give a view of how people attach meanings to HIV and AIDS. Some of these languages indicate how dangerous and fearsome HIV is to the Malawian society while the other terms are just a mockery of the individuals

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<sup>8</sup> Kachilombo means small animal

<sup>9</sup> Wavisanga is a tumbuka tribal language not a word from the local official Malawi's language. All the other terms are in Nyanja. Malawi's first local language

infected. This is to show; how different the infected individuals are from others, their lack of responsibility from taking precautions, dangers posed by the infection to the whole community and vulnerability or frailty of how human beings are.

The counselling training also highlighted some terms that were used as synonyms for HIV and AIDS; these were *matenda a masiku ano* (the illnesses of these days), *matenda aboma*, (government illness). Participants reported that people use this term to absolve themselves from taking responsibility over care of the sick and prevention of the infection. *Anyezi* (onions), and *kaliwonde-wonde* (a disease or condition that makes one thin), *kachilombo kamuufa* (a small animal in maize flour). The researcher asked for the meaning of *kachilombo ka muufa*. In response the one who had mentioned this term explained that; an animal in maize flour is a metaphor that relates sex to Malawi's staple food which is made from maize flour. His explanation indicated that sex is referred to a meal therefore one can not survive without eating. The other two names, onions and *kaliwonde-wonde* refer to the loss of weight in AIDS cases. The onion metaphor was translated as a simile for emaciation in AIDS cases to the stem of onion plant. Media languages such as AIDS scourge and victims were pointed out as stigmatizing to those infected with the virus.

These findings indicate the meanings that are attached to receiving the diagnosis itself and the beliefs that surround the transmission of the virus added to its complexity. These names could also relate to the ambiguity of sexual practices in the Malawian society. As it has been indicated earlier on that sex outside marriage is not accepted whilst on the other hand it is celebrated as a sign of socio-economic success. Therefore, the diagnosis of HIV or AIDS gives people a lot to talk about from the different categories of people among those who support it and those not supporting it as such everybody gives different meanings depending on how he understands the sexual practices. Goffman (1963) noted that stigma should be seen as a language of relationships that are used in daily discourses in forms of metaphors(19). Use of stigmatizing terms was also reported in studies that looked into HIV and AIDS related stigma in Uganda, Ethiopia, Tanzania and Zambia (85;86). The participants' narrated different kinds of treatments that they had received from others on the assumption of the claims that led to contracting the infection. These kinds of treatment have been given in detail in the next theme.



## **Chapter 6.0: The consequences of living with HIV or AIDS**

Participants were asked to explain if they had shared their results with other people. Their responses showed that some did share and others did not. They all gave reasons for their actions. Their narration showed that the issue of disclosure was a challenge to all of them at the time they had received their diagnosis. Participants' indicated that they had to be careful with the selection of whom and how to tell. They reported that they were afraid of maltreatment because of their status. It was also mentioned that they had problems to tell about their status because of shame. The issue of disclosure will be covered in detail in the next section.

The researcher asked to know the reactions of those who were told of the HIV test results. Some of the participants reported of having received mixed reactions from the people that they had told or those who had suspected them of having HIV. Some people encouraged and supported them while others maltreated them. Their narrations indicated a number of reasons why others maltreated them. That included; fear of contracting the virus, fear of social contamination, a way of punishing them and justification or validation of social- economic views. The key informants' interviews and the public discourses also shed more light on some of the treatments that PLWHAs received at different levels. Therefore, this section gives a view of forms of treatments and its contexts.

### **6.1 Encouragement and support**

Participants reported of receiving support and encouragement from their family members, friends, fellow parishioners and church leaders, employers, health workers and from other PLWHAs.

It was a common expression from all who had received encouragement and support that their friends/parents/employer/church leaders encouraged them by trying to show that knowing one's status is good for planning purposes. This indicated how difficult it was for one to decide and go for HIV testing. Most of the participants did not make decision to go for the test on their own. It was either through influence from relatives and/or a health worker. To most of them HIV testing was the last option they had to make when their doctors saw that their conditions were not responding to a number of treatments that they had prescribed for them. However, there were a few others who reported that they were encouraged by their relatives to go for the test. Almost all who reported that they were

encouraged by their guardians to go for the test reported that they received support and encouragement following their HIV diagnosis.

When we went there, I was told the same thing that I am HIV positive and my Uncle told me not to get worried since nowadays we cannot run away from the virus. He said you should not loose hope, this does not mean that you cannot do something in your life. It's even good that you have known your status and this can make you change your behaviour and move forward *(a 29 year male PLWHA married and a father of 1)*.

The participant in the quote above took a test following an advice from his nurses but he did not disclose to any of his family members. When his uncle saw that his condition was getting worse he suggested to him to go for HIV testing. He reported that he did not tell him that he had tested before because he wanted his uncle to get first hand information from the counsellor. He had mentioned that it was difficult for him to disclose his results at the beginning. This may mean that though families in the African context are believed to be the primary care givers to the sick members as indicated in the context chapter, with HIV and AIDS it is different. Therefore, those who were diagnosed were not sure of the kind of reaction that they could receive from the family members. However, some relatives accepted this responsibility, and supported the PLWHAs financially and materially.

The major help I get from my parents is food. As you are aware that I am not working they are able to buy food which is necessarily for me due to my status. They are trying their best to make all the necessary food for me available all the times. They also encourage me to go for afternoon prayers together with them. They tell me to put God in front so that he should protect me from committing sins. So they really help me spiritually *(a 30 year male PLWHA separated)*.

Food was one of the major concerns to most of the PLWHAs. This problem was also shared by the key informants as indicated in the quote below;

We are not very much satisfied with the care we are giving to these people because we do face a lot of problems like lack of food when we go to see these patients we do find them without any food or even having no guardian. Sometimes we do have nothing to assist them with in terms of food or money to buy food. You end up having un-peaceful mind because you automatically ask yourself to say this person should he really die because of lack of food? Even if we give them Likuni Phala<sup>10</sup>, that is not enough to keep them going because if the patient was a bread winner automatically the other dependants will eat the food together with the patient. There is no way that the patient could rely on Likuni Phala only. He also needs some other types of food. So the food we give them is not enough to keep them going. It's not easy for us the caregivers to accept this situation *(a female key info from the clinic home based care program)*

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<sup>10</sup> Likuni Phala is a porridge that is made from a mixture of soya bean flour and maize flour

Most of the PLWHAs were not working as indicated in their demographic information because of ill health or they were denied jobs because of their sero status. For the few who were working, their earnings were not enough to cater for the food that was recommended to them in the health education teachings. Therefore, it was difficult to most of them to have access to good nutrition. Those who did not have any kind of financial support complained that it was taking longer to get better because of poor diet. Therefore, food was regarded as a drug on its own. Those who had access to good diet reported that they were getting better because of following instructions that they were given on diet in addition to the medication that they were taking.

It was also noted from the observations at the clinic that other family members were supportive. Some escorted their sick relatives to the clinic while other guardians came to the clinic on their own to collect medication for their sick relatives. That is for those who were on ARVs. Some of the PLWHAs who could not sit on the queue for a long time had their relatives sitting in the queue on their behalf. Other guardians reported of coming to the clinic as early as 4.30am leaving their sick relatives at home and sit on the queue on their behalf. The sick were following later when the clinic was about to open. They were doing this to make sure they were attended to in good time.

Support and encouragement were also reported from some close friends that PLWHAs shared their results with. One of the female PLWHAs narrated in the quote below;

She started encouraging me not to get worried because if you are diagnosed with HIV does not mean that you are going to die very soon. Why are you getting worried? You were told about your status last week and nothing has changed in your life. There are other people who are also HIV positive and if you look at them you can feel sorry. You need to start planning for your future while continuing staying your normal life. She told her husband about this issue and they came to our house together that evening. Since that time she started supporting me even when I fall sick she made sure that I am treated accordingly. *(a 34 year female PLWHA, married and a mother of 2)*

This was a common expression in most of the PLWHAs that the researcher talked to at the clinic and some of the PLWHAs that she had talked to in the two support groups that she had visited. Most of them narrated that they were encouraged when they saw others who had similar or more problems than them but still surviving. Sosnowitz et al (1992) noted that people in stressful situations derive comfort

and encouragement by comparing and contrasting their problems, emotions and feelings with others in like circumstances(87).

Other few PLWHAs who were working reported that they had received support from their employers such as: paying for their medication at the hospital. This was at the time before ARVs were made free and that other employers allowed the PLWHAs frequent visits to the hospital.

It was also noted that some companies sent their clinical staff to Lighthouse clinic to train on ARV management to improve services at their clinics for their staff. Some employers featured on a television program (Pakachere)<sup>11</sup> explained of policies that they had put in place to support their employees living with HIV and AIDS. This showed commitment that other companies had on the welfare of their staff.

Some PLWHAs who disclosed their results to their church leaders and fellow church members reported of support that they were given as indicated in the quote below:

Then I decided to disclose my status to the church elder at our church who encouraged me to accept my status. He explained to me that it's good that I know my status because a lot of people don't know how they are in their body, including myself. He said “don't get worried because it's good to know how you are rather than staying without knowing your status. He told me to continue singing with my friends as I used to do, and when I have nothing to do, I can sit and read the Holy Bible to make myself busy. (*a 23 year male PLWHA, unmarried* ).

All the participants appreciated the support and encouragement that they had received at the clinic. Their narration indicated that since the time they had known their diagnosis, the clinic had helped them to cope through counselling on positive living and other medical support.

One female PLWHA indicated of support that she had received from her partner when the extended family members wanted their son to divorce her because of HIV diagnosis. Similar experience was also noted on one of the radio program (*Zam'maboma*)<sup>12</sup> which reported of a family where a wife was diagnosed with HIV. The husband's relatives told him to divorce his wife on the grounds that she had

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<sup>11</sup> Pakachere is a radio and television programs sponsored by international organizations that highlights issues that relates to HIV and AIDS

<sup>12</sup> a program that reports on issues that happens in all the districts in Malawi

received an HIV diagnosis. They indicated to him that he can contract the virus from her if he continued staying with her. The husband refused and indicated to his relatives that he could not leave his wife because of that reason.

The excerpts from the PLWHAs narrations of encouragement indicate that all who gave them the encouragement focused on the fatalistic views that people had on HIV infection. Statements such as being HIV positive does not mean that “it is the end of your life” and “HIV diagnosis does not mean that you can not do something in your life” may indicate the meanings that people attach to HIV in this society. This may also relate to the immediate reactions that participants shared of their reactions at the time they had received their HIV diagnosis. Others reported feelings of hopelessness and almost all thought their diagnosis meant that death was drawing near. What the PLWHAs narrated as their immediate reactions to their diagnosis and what they reported from what others said to encourage them may indicate that they shared the same meanings of HIV with them.

Interviews with both key informants and PLWHAs in addition to the data analysed from the public discourses highlighted that though others received support and encouragement, it does not mean that they had received these kinds of treatment from everybody who knew or suspected of their status. There were others who stigmatized them. Some who had found supportive services at one level received stigmatizing treatment at another level. For example some PLWHAs received support within their families and received negative reactions when they went to work. Others had some family members who accepted and supported them but other members could not, instead they were giving them different kinds of negative treatment. Therefore, the next section highlights forms of negative treatments that the PLWHAs experienced at different levels and the assumed reasons for the treatments that they had received.

## **6.2 Negative experiences of living with HIV and AIDS**

If it was in religious circles I would have chosen to use this term “ex-communication” for the negative experiences that participants of this study shared. This term ex-communication according encyclopaedia Britannia (2006) is defined as a “form of ecclesiastical censure by which a person is

excluded from the communion of believers, the rites or sacraments of church, the rights of church membership but not necessarily from membership in the church as such.” Narrations from some of the core participants indicated some similar experiences in the treatment that they had received in their social intercourse. Participants were excluded from social activities in the home, work place, community, among friends and others places. However, the exclusion of the participants did not stop them from being members of the family or the community but some rights were withdrawn from them. They were treated as “not quite human” though they were being regarded as members of the family or community. In this sense, I think the term excommunication fits with the experiences that participants shared in this study. I will borrow this term to give a clear view of what the study participants shared as their experiences of living with HIV and AIDS in the social intercourse. In this study the church has been substituted by different social gatherings that shaped the experiences that were shared by the participants.

The core participants’ narration and the key informants views on the reason why some PLWHAs were treated in an inhuman way indicated that the different treatments were related to a number of reasons that includes: fear of contracting the virus, in others it was given as punishment for diverging from the norms and disobedience to parents, others feared the social “contagiousness” of stigma and the last reason could be social and economic justification. Similar experiences were taken note of in some public discourses. Part of these experiences has been drawn from what some members of the HIV and AIDS support groups that the researcher visited shared. These experiences have been divided into 4 subsections. Effort has been made to categorise the treatments into different subsections of the assumed related factors though the experiences seem to be interrelated. It was noted that some of the treatments that were shared fall under one or two sub sections of the assumed factors but they have been given in one subcategory only.

### **6.2.1 Ex-communication related to fear of contracting the virus**

The PLWHAs shared their own experiences of ex-communication in their families, friendships and community. Other PLWHAs and some key informants shared their observations from what other PLWHAs have experienced. This most often was expressed in exclusion of the PLWHA in the social

interactions at family level and interaction with people in their neighbourhood. As one of the PLWHAs narrated in the quote below;

In short I can say that you do have time to chat with your friends, crack jokes and eat together. But when I tested positive all my friends ran away from me. Now they were making jokes because of my status. When they chat you could see that they are talking about my status. When I have some money and we decided to have some chips they were not allowing me to contribute some money from my pocket and told me to buy my own chips to eat lone. A lot was happening to me (*a 23 year male PLWHA, unmarried*).

The fear that HIV can be transmitted through sharing of food with the person infected was common in the participants' narration of how they were treated by their family members, friends and others. In one of the group therapies that the researcher had visited, one female PLWHA visibly sad, narrated that her mother who was staying in the same compound with her could not eat food that she was preparing in her house, she further reported that her own children were not allowed to eat with her from the same plate. Her tone of voice showed that she was saddened with this treatment as she was speaking slowly and sobbing at the end of her narration. Other PLWHAs also shared this experience that they were given separate utensils to use at home and that they were not allowed to eat from the same plate with others, some were even not allowed entry to the kitchen for fear of food contamination.

Most PLWHAs who were given their own utensils claimed that these utensils were kept separate from the rest of the other family utensils even after washing them. This segregation was not only limited to utensils and sharing of food. Others were not allowed to use the flush toilet with the rest of the family members, they were told to use the pit latrine outside the house in places that had those facilities.

Some key informants reported of PLWHAs who were put in isolation because of fear that they might get infection through contaminated air. They narrated of cases that were given separate rooms in the homes, others were relocated from the main house to the servant quarters in families where they had such services. One of the key informants, who saw this happening in one of the families, reported that the parents took their servant from the quarters into the main house and sent their infected daughter into the servant quarters. It was also reported that among the cases that received such kind of treatment

was a daughter of a Pastor. The daughter was given a separate room and was not allowed to mix with others. The key informant further indicated that the parents to this daughter believed that HIV could be transmitted through inhalation of air that is contaminated with the virus.

Similar experiences were also shared in informal conversation with one of the clinician who was involved in the home based care activities. He narrated of a patient whom he had been seeing as one of his cases in the community before the patient died. This patient had Kaporsi sarcoma (skin cancer) and was given his own room, where food was left on the door and patient had to crawl to pick his food. After eating the food he also leaving the plates on the same place and relatives could come push the plates with a stick into a basin and wash them in boiling water to avoid infection. The clinician further narrated that the patient was told to hold his mouth when talking to others. Neither her mother nor her husband could wash her dirty clothes. All her dirty clothes were thrown away after use.

One of the key informants also shared an experience of one PLWHAs who was about to be relocated. He was rescued by the members of the home based care group who had visited him at the time when the family was planning to build him a house. The key informant shared her experience in the quote below;

The problem is there even though most of the clients do not want to show that they are facing these problems but we are able to know that this is what our patients are going through. One of the examples, which I can tell you, is that we had a certain boy who was sick and was living with his parents in Area 10<sup>13</sup>. When we went to visit him, we discovered that the parents were planning to build a separate house for him because he is infected. He was expected to be staying alone in the house which will be self contained. This showed that they were discriminating him. So when we sat down with them they changed their minds and this did not happen. They understood the meaning of HIV and AIDS.

Sometimes it happens that when we have gone to see these patients you find them not feeling well. For example you find them vomiting and you need to give them start dose of anti-emetics because at times you have a feeling that if I leave the medication the guardians will not give them, you ask them to bring some water you will hear them saying can you bring some water in his cup, which shows that they have special cup for the patient. Sometimes we are told that the patient is not eating and we do ask them to prepare porridge for the patient and we wait for the porridge to be ready and you hear them saying have you put the porridge in his/her plate. This really tells us that the patient is being isolated. So we do call the guardians and ask them why the patient is having special plates and cups. Does that mean that the patients love these cups

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<sup>13</sup> One of the low density populated areas in the city where people have posh homes.



and plates? Then they are able to tell us that they thought that if they use the same utensils with the patient they may contract the virus and we are able to clarify. We do ask them whether they have been counselled and what the counsellor said if they were available when the client was being counselled. They are asked on the modes of transmission and they are able to explain the modes of transmission. We also ask them the link between the modes of transmission they have said to the use of same cups and plates. They were able to say that there is no relationship. The patients get tired and wonder why he has to use same cup and plates on daily basis from the time he started getting sick. They are able to relate that they are being isolated (*a female key info home based care*)

Some cases reported of being denied resources. One of the male PLWHA narrated of his case, his landlord evicted him from a house that he used to rent when he heard that he was a member of an HIV and AIDS support group. He reported that his family used to draw water from the landlords house. At the time, his landlord heard that he was a member of an AIDS support group in their community he asked him to stop drawing water from his house, later he was told to move out of the house. The PLWHA further reported that he had a hawker where he used to sell some food stuffs and other groceries, by the time that people around this place knew that he was HIV positive they all stopped buying from his hawker. He ended up closing his bussiness.

Some participants narrated of problems in their marriages because of HIV positive results.

When I started getting sick, we were together... we were together then the same month after being found like that with HIV, that's when the husband said you will infect me with HIV, that's when he chased me from his house and that's when I went to my sister at Area 47. (*a 38 years female PLWHA separated and a mother of 3*).

The interaction with the PLWHAs from the support groups and at the clinic showed that this was a common problem among female PLWHAs. Though some male PLWHAs reported of this experience they were only a few. Interviews with the key informants also confirmed this observation. It was also noted that in some cases extended family members were involved in trying to “rescue” their relative from contracting the virus from the infected partner as stated in the quote below;

...By that time I was admitted to the hospital and when he came to see me I disclosed my status to him. I even showed him the results and he just kept quiet, later on he said I told you not to go for an HIV test and when the doctor told you, you were supposed to inform me first instead of just going ahead and have the test done. I told him that even if I wait for you, you will not give me the care needed, but I saw that having my blood tested is one way whereby the doctors could know of how best to assist me with the right treatment. Then he went to explain everything to his mother and we reached to appoint where our family was breaking up. The mother came to the hospital and told me not to go back to my husband's house since I have AIDS. I don't want you

to stay with him again; you will end up infecting him (*a 37 years widow PLWHA and a mother of 3*).

The above statement indicates the gender imbalance that exists between men and women in Malawi. The husband expected her wife to wait for him to make a decision for testing. As she continued with her narration she indicated that she had been asking the husband to allow her to go for testing but the husband could not allow her. She took the opportunity that she was in hospital to go against her husband's instructions. Most of the female PLWHAs in the support groups that the researcher visited shared this concern. They had problems to convince their partners to grant them permission to go for the test at the time they had suspected of having the virus.

Other participants expressed concern with the kinds of treatment that they had received from healthcare providers. Participants complained of long waiting periods at lighthouse clinic. Others reported of being sent back for a number of times without being attended to. They reported that it was indicated to them that they came late after all the numbers were distributed. This was a concern in all the two support groups that the researcher visited. Some participants thought that the clinic was sending them back because the staff did not want to assist them. Talking with the staff and a report from NAC's Executive Director indicated that this problem was beyond the clinic's solution. It was to do with the allocation of resources per month according to the funding that they had received from donors. In addition to this, the long waiting time could be related to the understaffing at the clinic as already highlighted in the methodology chapter.

Some PLWHAs told of some unbecoming behaviours displayed by nurses in one of the big hospitals in Lilongwe. The PLWHAs indicated that some nurses showed no interest to touch the skin of the patients when administering injectable medication. An informal conversation with one of the Project Drs confirmed such practices and narrated her own observations of stigmatizing attitudes in another hospital in Lilongwe. This is where she had taken a beggar who had signs of full blown AIDS for treatment. She narrated that the man was admitted on the veranda of the male general medical ward. This ward is always filled to its capacity such that some patients are given space at the veranda to make their beds. The beggar was admitted on an isolated corner on his own, away from the other patients. The next day the Dr hired some men who washed him and changed his clothes. The Dr

indicated that he was surprised when she went to see him that she had found medication in a piece of paper next to his bed. This happened almost every day the Dr visited. That made her suspect that the nurses were just throwing medication to him. When the researcher asked the Dr, why she thought that happened. She claimed that it happened not because he was a beggar but because of the signs of AIDS that he had on his body.

The core participants' narrations indicated that the negative treatments that they had received and what they had seen been given to others changed with the disease progression. This experience was shared by a number of PLWHAs who had suffered from AIDS defining illnesses and recovered. Their narrations indicated that at the time they had signs of an AIDS defining illness they were stigmatized and discriminated by many people around them as stated in the quote below;

I could see what was happening to me and asked myself that is this the way an HIV infected person is treated? It was really difficult when I had some sores in my hands, nobody was willing to wash my clothes, and even the children could not touch my clothes. We could not eat together and I was using my separate utensils because they were afraid that they would contract the virus from me. I continued leading such type of life and could visualize that it's really true that people who are HIV positive are discriminated in these locations. I don't know possibly people are not sensitized on how to care for HIV and AIDS patients in the community. May be some people lack some knowledge on HIV and AIDS and I could think that if it were their child, how would they look after that child. I reached a point of getting other people to work for me like washing my clothes, *(a 29 years old male PLWHA married and a father of one)*

He narrated that when his condition had improved and he regained his strength people who had discriminated him started sharing food and utensils with him. This was also reported by other PLWHAs as stated in the quotes below;

I mean that aah, I don't know whether it's God's plan because I don't have signs and symptoms which can make someone conclude that I have developed AIDS. I am able to do things freely. The picture that I have HIV is now removed from people's mind and they take me as a normal person now *(a 23 year male PLWHA, unmarried)*.

I should thank God because when I started ARVs. I responded very well and came back to normal before people concluded that I should have AIDS I only suffered for a short period of time. So our friendship was not disturbed *(a 46 years female PLWHA married and a father of 5 children)*.

As highlighted by these narrations it is patent that the shape of stigma is entwined with the course of the illness. The narrations indicated that the 3 issues that were raised by Jones et al (1984) in the six

dimensions of stigma – peril, aesthetic, and concealability – came into play with the PLWHAs' experiences of stigma during their illness progression<sup>(79)</sup>. The narrations have indicated the effect of the “course and concealability of the mark.” In case of HIV infection sometimes it can take a number of years for the signs and symptoms to manifest. During this asymptomatic phase, one can hide the HIV status. Using Goffman's terminology, we can refer this situation to a “discreditable” position whereby the infected individual alone knows that he possesses an attribute that is socially discrediting. Then after some time the signs start to show. This is the time that one can not hide the status then he moves from discreditable to discredited position<sup>(88)</sup>. Muyinda et al (1997) in a social aspect study of AIDS that was conducted in Uganda found that PLWHAs tried to keep away from public places and other men started putting on long sleeved shirts when signs manifest on the body. For the participants of this study, this was not the case because they received negative treatment from the people they had lived with therefore covering up could not have been possible.

It was also noted that aesthetic, one of the dimensions of stigma developed by Jones et al (1984) played a role in influencing the kind of treatment that was given to some PLWHAs like in the stated case of a PLWHA who had Kaposi Sarcoma as well as the other case that had sores in his hands. Both narrated that relatives could not wash their clothes and they were made to eat on their own because of the “physical blemishes” that appeared on their bodies.

Both PLWHAs and the Key informants claimed that these treatments were given due to lack of knowledge. However, others felt that the treatment could be related to lack of love on the persons infected. As indicated in one of the key informant's narration quoted above, when she tried to assess the levels of knowledge on mode of transmission in some of the stigmatizers, it showed that they knew the mode of transmission but it existed with some doubts and in others knowledge existed with some misconceptions. This may indicate that fear of contracting the virus through casual contacts and misconceptions persist despite the knowledge that people have on the modes of HIV transmission. The Malawi behavioural surveillance survey (MBSS) (2004) indicated that misconceptions on HIV transmission still exist but varied among different groups that were targeted in the survey. The report indicates that over 90% of the Police officers who had participated in this survey believed that HIV could be transmitted through sharing a meal with an HIV infected person as compared to over 75% of

teachers who had no misconceptions about HIV transmission(89). Jones et-al (1984) claimed that the focal point of stigma is fear(79). The narrations from the participants and analysis of discourses confirm this claim. Fear of contracting the infection was the most common reason that participants gave for the un-just treatment that they had received from different people including family members. Jones also claimed that fear is more likely to lead to rejection (ibid) as indicated in the excerpts above almost all participants who had shared their experiences of stigma reported of rejection from their social relationships.

## **6.2. 2 Ex-communication related to punishment**

The narrations from both interviews indicated that having HIV infection was considered as a product of personal choice as one PLWHA indicated in the quote below;

Most people think you contracted the virus because you were careless and they don't need to suffer because of you, you were doing it deliberately. You were using your money a lone, you did not use the money with us because they know that for you to contract the virus you had enough money to enjoy with and you were not assisting them. But when you fall sick you now trouble those people whom you did not care when you had a lot of money. They would now start taking care of you. But still they will remind you about the money you wasted when you were okay and enjoying. *(A 34 year male PLWHA married and a father of 2)*

All the PLWHAs and the key informants shared the view that People living with HIV are considered as people who had invited the problem on themselves. The money issue in men is mostly associated with multi-partnered sexual networking since higher economic status renders some men an opportunity to negotiate sex with women in exchange for money(66).

One of the key informants indicated that contracting the virus means that one “volunteered to misbehave”. This is most often related to the tendency of linking HIV and immoral behaviour as indicated in the quote below:

Madam, when this disease strikes, it doesn't attack a person anyhow. It is like somebody between a man and a woman volunteered to misbehave, promiscuity. With promiscuity it is obvious that you can contract the virus. So if a person whether a man or a woman is HIV positive, that person is perceived to be promiscuous. And the affected person tries to run away from the perception that people have on them. We all know that this is a communicable disease (wopatsirana). If it's a woman, they are called Prostitutes. If they are men we use the same name even though that this name is mostly used in women. If we say communicable disease means it can be transmitted from one person to another which means you disobeyed one rule, you made a mistake somewhere that's why you have found yourself landing into such problem. So the origin of the

disease or how one gets infected with the disease is what makes them feel ashamed. So if you have AIDS means that you were promiscuous but only that people didn't find you in the act but having the disease has revealed to people, even to children that you have been promiscuous. This disease is transmissible you contract it yourself. (*A male key info, one of the patients' guardians*)

This statement indicates that the diagnosis of HIV or AIDS reveals the infected individual's previous hidden promiscuous behaviour. Using Goffman's (1963) theory, the diagnosis transforms an individual from discreditable prostitute (known to oneself) to discredited prostitute (known to the public)(19). This narration also indicates the saturation of the beliefs that surrounds the origin of the infection as indicated that even children can connect HIV diagnosis and promiscuity.

Some of the PLWHAs reported of verbal abuse among other negative treatments that they had received from their family members. . For example statements like “*we were not there when you contracted your illness.*” The PLWHAs expressed concern that such messages make them feel sorry about their situation. It was noted that these messages were meant to show the individuals infected that they need not to bother their guardians because it was considered as their fault for contracting the virus. It was also sent to remind the PLWHAs of the time they contracted the virus. This is the time that the PLWHAs are believed to have had a lot of money that led them into promiscuity if it is in men. While for women it is time that they are believed to have had sexual partners who could give them a lot of money in exchange for sex. MBSS (2004) indicated that use of statements such as “you are reaping what you sow” are commonly expressed towards people who were believed to have had “reckless” sexual life(89). These kinds of expressions were also reported in an ethnographic study that looked into HIV and AIDS stigma in Zimbabwe(83).

Some participants indicated that receiving HIV diagnosis was regarded as punishment for one's disobedience as one PLWHA indicated in the quote below;

To me, I take this as punishment due to my disobedience that made me to be infected with the virus. By disobedience I mean... when I dropped out from school in 1997, I told my parents that I want to get married. My parents rejected the woman I showed them. With my own decision I decided to marry this lady and I bared two children with her. That's when I was found with this disease, so my parents were refusing me to marry in that family. Saying people of that family have a bad life style. (*A 29 year widower PLWHA and a father of 2*)

Children in Malawian culture are expected to take advice from their parents or other elders regardless of age. The quote above may also indicate the responsibility that parents have in helping their children

to make right choices for their lives and the impact that it reflects when one makes a choice that is contrary to the parents' decisions.

Some church leadership were reported of condemning PLWHAs in the way they preached their ceremonies or give counsel to some people infected. One of female PLWHAs reported of her experience that their church leader preached about HIV infection as a curse from God because of people's disobedience. She claimed that the church elder preached this message because he had seen her condition therefore he was able to relate it to HIV. Similar experiences were also shared by some key informants as indicated earlier on. Some discourses confirmed such type of attitudes from church leaders as indicated in the context chapter. This kind of expression was not present in the church leadership only, it was also noted in some church members who shared similar beliefs. A chat with some of the Pentecostal Christian members confirmed this observation.

During the interviews the PLWHAs did not come out clearly with negative experiences with the church as it is indicated in the context chapter. This might be related to the reasons that most of the participants did not disclose their status to the church members. Some of the PLWHAs who had indicated that they received support and encouragement did not disclose their status to the church members. Since the church has an obligation to care for the sick members, the PLWHAs receive similar treatment just like any other sick members of the church.

Jones et al (1984) claimed that some marks are characterized by negative or punitive treatments because of the responsibility effect on the marked individuals. This is to do with the origins of the "mark(79)." If the marked is believed to have taken responsibility over the origin of the mark then the "just world hypothesis" cited from (Lerner 1970 in Jones et al 1984) is applied. That indicates that the "world is a place where people get what they deserve and deserve what they get(79)." This could be one of the reasons why some PLWHAs were given punitive treatment. However, Awusabo-asare (1995) noted that AIDS as a disease that has no cure is often interpreted as a form of punishment for disobedience(90). Also Ogden and Nyblade (2005) in a synthesized report of HIV related stigma in three African countries and Vietnam indicated that affliction is often perceived as an outward manifestation of moral transgression(84). Therefore, it all goes to the hypothesis of the "just world."

### 6.2.3 Ex-communication related to fear of social contagiousness

This is associated with fear of character flawed because of being seen in association with stigmatized individual. Some participants reported of the tension that existed in their marriages because of HIV diagnosis.

I did not disclose my status to him because of his bad behaviour. Everybody really knows the behaviour of my husband. If I just disclose my status to him definitely I will be chased out of our home. Even when I was diagnosed with TB he said he doesn't want to have patient at his house. It's better if you move out and go to your home village so that people should look after you, not me. I stayed two weeks before being taken to any hospital and he even told me that if you want to die, just die. His sister knows that I am HIV positive but she doesn't know how to disclose my status to him (*A 46 years female PLWHA married and a mother of 5*).

The above narration highlighted some difficulties that female PLWHAs had gone through at the time they had learnt about their HIV diagnosis. Almost all the female PLWHAs shared the view that they had problems disclosing their HIV test results to their partners because they feared that their husband would divorce them. Most women risked losing their marriages because of disclosure of HIV test results as indicated in some quotes earlier on. The above quote also indicates the problem that men have in caring for the sick. It was noted from the female PLWHAs narrations that men do not care much like women do when men get sick.

Some female PLWHAs from the AIDS support groups that the researcher visited indicated that their partners chased them or left them because of fear of contracting the virus. Others narrated that their partners told them not to disclose their status to other people. They were told to keep it as a family secret. The narrations from both interviews indicated that though some men indicated fear of infection from their partners they were the ones who brought the infection to their wives. Almost all women PLWHAs attributed their infection to their husbands' immoral sexual behaviours. Interviews with the key informants indicated that men excused themselves from taking responsibility of caring for their sick partners by indicating that they feared that they might contract the infection. This was so because culturally, men are brought up with a mentality that caring is a role for women. It was also noted in the key informants' interviews that the other reason could be that some men did not want to be associated with this "shameful" condition. Therefore, they run away from their wives to disassociate themselves from it.



It was indicated in the interviews that some parents denied responsibility of taking care of their sick children. Participants indicated that this sometimes is related to disobedience and parents don't want to be associated with the shame that their child's infection might bring to the family.

When parents bear children, it is expected that children should obey their parents. So if a child is found with a disease that shows that this child was not obedient. It's like parents were not instructing them on what to do. And these parents will be ashamed for not bringing up their children well (*a 29 year widower PLWHA and a father of 2*).

Some parents who did not want to be associated with this failure gave their children a kind of punishment to show that they were not part of the child's behaviour. The kind of punishment differed from one PLWHA to another. Others reported of verbal abuse by their family members and others omission of some activities of daily living such as providing the patient with proper food. Some reported that they were told to go and stay away from their parents.

It was unbelievable to hear gruesome and nasty experiences that some PLWHAs had gone through. One female PLWHA narrated that her relatives burnt her house at night while she was in the house. She managed to escape without being hurt. She narrated that she thinks her relatives wanted to kill her because they had been telling her to move out of the compound with her virus. At the time she narrated this she was living in a rented house and the Catholic Church was paying for her rent and necessities for her upkeep.

Some female PLWHAs indicated that some family members from their husband's family were not interested in them when they learnt about their HIV sero status.

At one time when I went there to deliver some materials to his Grandmothers, he had four of them and also some clothes and food for his mother, nobody attended to me the way they used to do in the past. The Children would run and get what I had brought for them. But on that day I could see that even the Children were not interested to be closer to me, my in-laws were chatting on the Veranda and the moment they saw me they entered inside the house. I was welcomed by my Father In-law who greeted me and then went inside the house again, leaving me on the veranda. He spent some couple of minutes without coming back to me again. I was wondering what was happening because neither of the children or my in-laws came to greet me. Then after some time my mother In-law came out and greeted me, then went on to ask me what had brought me to the village and how their son was doing. I responded to her that everybody is doing fine and I have come to deliver the materials and food which my husband bought for them. She just stood up got the bag and removed everything and gave me the bag. I could see that she was not interested in me I stayed there until when a cousin to my husband

called me to his house. She told me to leave that same day (*A 37 year female PLWHA, widow and a mother of 3*)

This narration indicates how HIV diagnosis makes people repellent to others around them. She indicated that before receiving of HIV diagnosis she used to live in harmony with her husband's family members. With the HIV diagnosis things changed. This could be related a number of factors that includes: fear of social contamination, the family members feared that they might be associated with immoral characters for their association with somebody who is considered as "immoral." There is also a possibility that relatives feared the contagiousness of the infection itself. The other factor could be that the relatives feared the social and economic burden on their son who was the bread winner for his family as well as his parent's family. This could be associated with prolonged illness from most of the AIDS related illnesses. A study that Awusabo-Asare conducted in Ghana in 1995 indicated that when a disease that is associated with sin occurs in a family, some members of the family distance themselves from the shame and ridicule that the disease carries with it(90). Jones et al (1984) indicated that people who associate with the stigmatized are likely to be stigmatized(79). In the same vein Goffman (1963) claimed that the family members of the stigmatized are obliged to share the blame(19). Therefore, it is probable that family members and others did not want to be associated with the shame that could be brought to them by HIV or AIDS diagnosis to the affected members. However, there is a possibility that others did not want to associate with PLWHAs because they feared the responsibility of taking care of the infected individuals when they get sick.

#### **6.2.4 Ex-communication related to justification of social- economic views**

Interviews with PLWHAs indicated that some of them had lost their jobs because they had either disclosed their HIV status or they were suspected of having the virus. This was reported to be common in people who had informal type of employment. Some of those who had formal type of employment reported of mistreatment that they had received from their employers. Others indicated of having received premature retirement on health grounds. One of the female PLWHAs who had worked in one of the banks at the time she was diagnosed with HIV shared her experiences.

Then in 1991 my husband died in July, in September I got promoted to a position of a ..... it was like Bottom line Manager, I was working as acting for almost 4 years. Some of my friends were being confirmed after a year except me. Then, I went to the human resource manager to find out how long I was going to be on the same position as acting supervisor. So he said your name is included on the next promotion list. You will now shift from being acting to a full (...) Then, there was a policy at the (...) that when you have reached the position of an officer, you need to

shift from Area 18<sup>14</sup> to Area 47<sup>15</sup>. As for my sake I moved from being a bank clerk to supervisor jumping one step of being the Officer but I was left in the same Area 18 from 1991 – 1994, I was writing a lot of letters to them trying to find out what was going on since some of my friends who joined later were being moved to Area 47. I was trying to find out the reasons why I was not being transferred and I could not get responses from them. At that time most of the supervisors were staying at area 43. When we reached 1994 October, that was when I was given a Flat at Area 11. So when I went to see the Flat I told them that it was too small to accommodate all my personal belongings. Then they insisted that just move for the time being and while you are there you can now come to complain so that you could then be considered to be given a bigger House. So they started moving me from one department to another and I noted that the whole Idea was to find some faults on me since management was not comfortable with my status and wanted to find some reasons of dismissing me out of work. I was ill-treated so that I should be frustrated. Each time there was a transfer my name was on the top list. I was being shifted from one place to another. I was just observing what they were doing. I told myself that I would just accept what was happening to me because I had the responsibility of taking care of my kids. I was taking both the responsibility of being a father as well as the mother and if I had to resign what would I do to look after them. They got to a point where by as a supervisor I was told to go and work at the (...) Before I went there I was transferred to do auxiliary Services which deals with supervising clinic, cafeteria and sports. I was supervising (...) on Foot Ball and Volley Ball. Then I argued that there were other people within the (...) who have been employed solely for sports and yet they are doing clerk work for the (...) and for me I came in as a Clerk then why should I be assigned to sports activities (...) *(a 42 year female PLWHA a, widow and a mother of 2)*.

The narration in the excerpt above might indicate fears that the (...) employers had towards the contagiousness of the infection. In 1991 the messages about HIV and AIDS were not as explicit as it has been in later years. This could be related to misconceptions that surrounded the mode of transmission. As it has been indicated in the contextual background, in those years HIV infection was associated with death. It is probable that the bank employers thought it was a waste to spend a lot of money and resources on an employee whom they thought was going to die within a short period of time.

It was also indicated in one of the ARV group adherence counselling at the clinic that some employees were threatened by their employer's policy of dismissing people whom they had suspected of having HIV infection. The participants expressed this concern when the nurse who conducted the counselling session asked if the participants had shared their results with relatives or others. One female PLWHA who was employed by an Asian business reported that her employer was telling his employees that their business was for profit making as such they could not keep sickly people to work with them. Again she mentioned that the employer always said that he could not manage buying coffins now and

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<sup>14</sup> Area 18 is medium density low populated area

<sup>15</sup> Area 47 is a low density populated area

then. Therefore, this woman had to keep her HIV status in secret. She made sure, to use her lunch time to collect her monthly medication at the clinic to minimize excuses that could lead her employer to question her healthy.

Other PLWHAs reported that they had failed to secure jobs because of policies that required them to go for HIV testing before employment was offered.

The time I went for testing I was working. After testing people came to know my status and were talking a lot about me. Due to this reason I decided to stop working and come to stay at home. While here, I have been looking for a job and done some interviews. Apart from marketing course, which I have done, I have also done driving. I did some interviews at (...) and other places. I have been disappointed at (...) because I passed the interviews but I was told to go for HIV testing and that put me off. I just gave up because I saw no reason for going for an HIV test when I already know that I am HIV positive. So I decided to disclose my status to them and they told me that they couldn't offer me a job. As of now I am not working and I am afraid to go to these other companies to look for a job because I feel that I will be told the same thing to tell them my HIV status (*a 30 year male PLWHA, separated*).

The stated PLWHA was visibly sad at the time that he shared his experiences. The knowledge of his HIV diagnosis has incapacitated him (refer to the case in the context chapter). The diagnosis overrides all the skills and knowledge in him that the employers look for when recruiting employees. The PLWHAs narration indicated that they were perceived as people with no future or hope as such they were considered as unproductive. MANET (2003) reported similar findings in a study that looked into stigma and discrimination(91). A report from the International Centre for Research on Women indicated that this kind of treatment is attributed to the common belief that PLWHAs should take lighter jobs because of the detrimental impact that hard work might have on their health(92). Therefore, this could be the reason that the PLWHA were denied employment opportunities.

It was also noted in one of the group therapies that the researcher participated in that other PLWHAs were denied fertilizer coupons for purchasing subsidized fertilizer and others business loans in their neighbourhood. They gave reasons that they were regarded as sick people who could not do anything like cultivating crops. As a result they were told to join AIDS support groups indicating to them that, that is where they can get support relevant to their situation. It is very unfortunate that some of these negative treatments came from community leaders. One male PLWHA in one of the support groups claimed that his name was erased from a list of people who had registered for food for work program.

He thought that some people told the chief through gossip about his status. The chief told him that he had been removed from the list because he was a sick man and could not have strength to do such kind of work.

Looking at what the PLWHAs have gone through it is similar to what other studies that looked into HIV related stigma have found. These were studies that were conducted in the following countries; Uganda, Ethiopia, Vietnam, Zambia, Tanzania and Zimbabwe. These studies indicated that the negative depiction of people living with HIV and AIDS in languages, metaphors and pictures reconfirmed fears, avoidance and the isolation of the infected individual(82;84;85).

The experiences that have been expressed in this chapter are closely interrelated. They all indicate the barrier that HIV and AIDS create between the healthy and the unhealthy, the moral and the immoral. These experiences indicate that the moral value reduces individuals into objects of in human behaviours. As indicated by Goffman (1963) that the stigmatized individuals are viewed as “less humans” such that they are ex-communicated in social interactions and this reduce their life chances. This is typical of what the study participants shared.

Neuberg in Lorentzen (2003) claimed that living in groups is adaptive with benefits from sharing individual efforts, resources and knowledge(93). Therefore, those identified as threats to the groups functioning are identified and excluded. In a way stigma serves the purpose of strengthening group solidarity and at the same time communicating groups’ values and norms to its members. Lorentzen (2003) suggested that contagious infections such as HIV that are considered as threatening to physical health are also considered as a threat to group functioning since individuals would want to remain health and contribute to the group functioning. Therefore, this might be one of the reasons why PLWHAs were excluded in employment opportunities, family and community activities (ibid).

## **Chapter 7.0: Management of reputation in the community**

It was noted that the general public has mixed views on disclosure of HIV and AIDS diagnosis as the cause of death in funerals. One of the radio phone-in programs<sup>16</sup> came up with a topic to investigate the listener's views on the issue of disclosure. 53 people participated in the program, out of these 4 gave neutral views such as relatives should be asked for consent, 22 were for the idea that HIV should be announced as the cause of death and 27 indicated that it is not good to announce. All the people who had participated in this program gave different reasons of why they came up with these views. Those who supported the idea indicated that it will be good for prevention so that if the bereaved left a partner people should avoid him/her for marriage. Those who were against it based their argument on the negative consequences that this announcement would have on the remaining family members.

This was also noted from the PLWHAs who participated in this study. Almost all of them indicated that they had problems to disclose their HIV status to their family members such as; sexual partners, parents, friends and others. The participants' narration indicated that the challenge of disclosure to partners was equal in both male and female PLWHAs. The fear that the first one to test among the partners will be blamed as the one who brought the infection into the home was one reason that PLWHAs gave for keeping their status secret. This was also indicated in some key informants interviews

Most of the experiences that we have been seeing are that possibly the husband or the wife would come for HIV testing without the knowledge of the other partner. They go home and stay quite. When they start having AIDS that's when we face problems especially if the one who is sick did not come for testing. Other clients would go for testing and start ARVs without telling the partner. It becomes very difficult for this other partner to tell the sick partner to go for HIV testing because of fear. This goes up to a point whereby they get support from the home based care group. The husband would reach the point of being bed ridden and being unable to go for HIV testing while the wife is okay is taking ARVs without the knowledge of the partner and partner is sick. This really becomes a challenge to us because we are not supposed to disclose the status without the consent of the HIV infected partner. Therefore, we try to advise them to go for counselling together as a couple and pretend as if they have never tested before. The aim of doing this is to assist the sick partner to go for testing (*a female key info from home based care*)

Some of those who disclosed took almost a day to 4 months to disclose their status. The researcher asked why they had acted the way they did. Those who had disclosed reported that; they had disclosed

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<sup>16</sup> the program comes on Capital FM, one of the Malawi's radio stations

to their friends because they were the people who gave them support. Some indicated that they had told their friends who had shared their HIV status with them previously. Lastly, others indicated that they wanted their significant others to know of their problem.

I disclosed my status to my wife late, I also disclosed to a certain friend of mine (name of friend), that's why I am suffering. It is because I am HIV positive. I emphasized to him not to tell anyone else. I said that I have told you as someone from my home village. When I die you should know the cause of my death that I have died of AIDS. I did this because he was telling me to go to the traditional doctor. I refused because I knew that it's because I am HIV positive. My wife was not insisting on visiting the traditional doctor. Other people were the ones talking about taking me to the traditional doctor (*A 34 years male PLWHA married and a father of 2*).

Most often death of young people in Malawi is associated with witchcraft, especially if the death is for a close member of the family. A survey that assessed the knowledge, perceptions and the causes of death among family members in one of the districts in Malawi indicated that death of a more distant relation makes AIDS more likely to be recognized as a cause of death(94). This denial could be an indication of HIV and AIDS related stigma.

When the PLWHAs were asked the reasons why they had to choose whom to confide in with their HIV status, some indicated that they feared the negative reactions from others around them. Goffman (1963) identified this kind of fear as felt stigma(19). Others reported of preventing their relatives from worry. Some narrated that they could not disclose because they were ashamed as most of them referred to AIDS as a "shameful disease." Lie and Biswalo (1996) reported of similar findings in a study that focussed on the choice of significant other to be informed about the HIV-test result in Arusha, Tanzania(95). Though the participants' narration indicated of these fears, almost all shared their results with one or two people that they had trusted. Awusabo Asare (1995) claimed that choice of a person to confide in with HIV and AIDS diagnosis is influenced by the PLWHAs perception of the reaction of the recipient to the information(90).

Other participants indicated of problems that came with lack of disclosure.

There is no benefit to me and I don't have peaceful mind because of this. When I went to NAPHAM I shared my situation with other members and they encouraged me to take him slowly and may be he might be encouraged to go for testing after some time. As of now I think he said that we really need to go for the test, because there is one of my friends who had been diagnosed with HIV and now he looks very health. He has gained a lot of weight. I asked him what is his opinion and he said he still need time to think over it. Now he is giving positive

responses on the testing issue. But I don't have peaceful mind (*A 46 years female PLWHAs married and a mother of 5*).

The above stated case tested and could not disclose to partner instead she insisted to his partner that they should go together for testing. Goffman (1963) states that when a stigmatizing attribute is only known to self, management of information about the stigma becomes central in social contacts (88). The individual debates on whether to tell or not to tell and if he/she is to tell to whom, when, where and how (ibid). The participants' narration including the above stated case indicated that they knew they needed to tell their partners or other immediate guardians of their diagnosis at the time they had just tested. However, they reported that they could not tell because of what they had seen others going through. Some PLWHAs took their time trying to find strategies on how to break the news to them.

The time I disclosed to her I did it slowly. I started by telling her that we need to go for an HIV test together because I feel that I need to know my status. My wife said that you need to go for the test first and when you disclose your status to me I will then go to be tested and disclose to you too. I told her we can go together but everybody will be given the results alone. It's up to you to disclose your results to me provided each one of us knows his/her status. She then refused to go for testing. Then after two weeks I decided to tell her my status. So I showed her the results and explained..... (*a 29 year male PLWHA and a father of 1*)

This was a test to find out how the partner could react to the positive status if the one infected was to disclose his status. The PLWHA in the above quote disclosed to his wife after 2 months and this is when he saw that his health had improved for the better. He indicated that he chose not to disclose at the time he was very sick because he feared that the wife would be emotionally affected.

Some participants reported of social withdrawal because of fear that frequent interactions would reveal to others of their changed behaviour which might arouse questions. Goffman states that relationships require sharing of information, demands a lot of time together with others therefore management of one's identity can have a negative impact on relationships (88). In regard to Goffman's claim, the need to conceal information can weaken relationships with time. To avoid suspicions some PLWHAs chose to avoid their previous social circles as indicated in the quote below;

Of coarse such things happened. People who used to be my close friends are no longer mixing with me any more and those who were not close to me are the ones who are my best friends now. And also most of the people who are my close friends now are those who are leading Christian life. Mostly I chat with Christians so that I can have spiritual benefit. So those people I used to



mix with before knowing my status are no longer my close friends. I changed now I am mixing with Christians (*a 29 year widower PLWHA and a father of 2*).

The narration from those who feared negative reactions from the public shared the view that people talk a lot when they hear that one has been diagnosed with HIV or AIDS. As indicated in the quote below:

I had these feelings because there are a lot of things happening to HIV positive people and the moment they learn that this person is HIV positive you would not like the way they talk about you. You could think you may be doing something that people should not see you; or you should not live. They will start gossiping that such such a person has been found with the virus. They will try to inform a lot of people about your status (*A 29 year male PLWHA married and a father of one*).

Because People who have HIV are not respected in our communities, we chat in our locations. There was a certain lady who was also positive, she could come to me depressed and I was encouraging her. I asked her the reasons why she was always depressed and she said it was because her husband had passed away. So I told her that my husband had also passed away. Then she further said that she disclosed her status to other people and they usually laugh at her anywhere she goes. Even when she goes go to draw water people laugh at her. The problem is that she disclosed her status to a lot of people thinking that they will sympathize with her but now they are laughing at her. (*A 54 years widow PLWHA and a mother of 4*)

The participants' narrations may imply that their fear came from experience of seeing other PLWHAs who had received unfair treatment because of their HIV positive status or their own experiences with stigma in a particular setting or relationship. Almost all the PLWHAs expressed fear of gossip if their status were to be made known to other people that they considered as not trustworthy. They indicated that people gossip on how the infection was contracted. This meant that the individual's behaviour is analyzed to find out where he messed up to land into this problem. Others indicated that they feared that people could gossip about their upcoming death and that they will live in expectancy of seeing physical changes in the infected individuals.

When we are chatting and talking about HIV and AIDS most of them think that for one to contract HIV means that this person has been going out with other people having sex with them. I have noted the way they talk. Most of these don't know that I am HIV positive because I am fat and look health. At our school they talk bad things about people who are positive. They even have a list of those people who are sick as being HIV positive and that they will die very soon. When I try to talk to them that there are other people who have HIV but they look health they don't believe it can happen that way. They feel if you are HIV positive you can not stay more than a year. I even gave them an example of a certain woman who was featured on the TV<sup>17</sup> as living positively for some years but still could not believe it. Most of the people hide their status

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<sup>17</sup> TV - Television

in their working places because of such attitudes (*a 34 year female PLWHA a primary school teacher and a mother of 2*).

Participants narration showed that their fears emanated from what they had heard others gossip about those that they had suspected of having the virus. Similar findings were reported in a study that looked into presence of HIV and AIDS in men's informal conversations in Southern Malawi (40).

The narrations from the participants' showed that the choices that the participants made were not without a cost. In others disclosure helped to access support and encouragement. However, the same disclosure in others led to abandonment and broken marriages as indicated in the quote below;

I went for VCT alone and my results were positive. When I went home I disclosed my results to my wife at home. From that time she went to her mother and disclosed my results to her, who in response advised her to leave me and go back to her mother (*a 30 year male PLWHA, separated*)

This statement may indicate one of the reasons why PLWHAs feared disclosure of their results.

Some of the participants reported of having joined the HIV and AIDS support groups in their communities but some of them did this without the knowledge of their relatives or their close neighbours. This was highlighted at the time the researcher visited the support groups. The participants explained that when they meet on the streets they do not introduce their fellow friend as somebody that they meet with at the support group. The researcher was instructed to do likewise. This was also noted in the informal conversations with participants at the clinic some indicated that they had no problems to be seen around the clinic premises since who ever sees them there can not go out to tell others because that will breach their own privacy of being found at this clinic. This shows that though others were free to come out they opted to do that to other people with similar problem like them

Looking at the experiences that have been shared in chapter 6, it is not surprising that many PLWHAs chose not to disclose of their HIV positive results. Though the PLWHAs indicated that they appreciated the need to disclose their HIV status, they had failed to do so. This was because they had learnt through other PLWHAs experience that disclosure can bring about negative repercussions to self and others through the notion of social contagion. Though this was the case participants shared of their experiences of how they managed to socially cope with their illness. Therefore, the next chapter will highlight on how participants managed to cope and tried to reinstitute themselves back into the society where they

had been ex-communicated as indicated in chapter 6. Some of the participants referred to the receiving of HIV diagnosis as the “beginning of new life” in reference to all the life transactions that people undergo following an HIV or AIDS diagnosis. Therefore, the next chapter has adopted this expression but into the opposite direction. The participants meant ex-communication while the beginning of new life in the next chapter means reinstitution into the society as a full member.

## **Chapter 8.0: The beginning of new life**

### **8.1 Living Life to the fullest**

The researcher asked how the participants managed to cope socially with their HIV status and the problems that they had encountered. In response participants reported a number of strategies and support systems that had helped them to cope.

Soon after discovering that I am HIV positive it was difficult for me to believe it. I was sweating a lot but still since I accepted my status then I came back to normal. It did not take long to stabilize. Aah I can say from the time I got tested, It took me 30 to 45 minutes but still after some counselling that this is not the end of my life and after I established that people have been living with the virus for 20years I had the hope that I can also survive with the virus for many years (*A 45 years male PLWHA and a father of 2*)

The above statement indicated that the participant’s interaction with the counsellor and the knowledge that he was given at the time he had received his HIV diagnosis helped him to accept his HIV diagnosis. Though the participant indicated that he had “accepted” his results, most often this meant that the participants could just give in to their situation because they knew there was nothing that they could do to change the situation. However, this was not uniform to all the participants especially to those who had indicated that they did not expect to receive such kind of results. Their narration indicated that it took them some time to understand what had happened to them before they negotiated to incorporate the diagnosis into their life activities. Nevertheless they narrated that with time they negotiated their status and they finally incorporated their status into their daily life activities. This might as well indicate that following a period of denial of the status participants noticed that there was no meaningful change that this denial brought to their situation. Therefore, they had to succumb to the situation and started living positively with the diagnosis.

Some participants narrated that they managed to negotiate with their status because of the “understanding” of their relatives.

Okay, understanding of my relatives and also encouragement from my fellow Church members through prayers (*a 30 year old male PLWHA, separated*).

The term “understanding” may indicate that receiving support and encouragement from others following a disclosure of HIV test results had something to do with how others made a meaning of the origin of the HIV diagnosis as indicated by Jones et al (1984) earlier on (79).

Those who did not receive support from their immediate family members reported that they had difficulties coping with their diagnosis.

...She asked me why I had said so and I told her that it's because of what was happening to me; people are not considering me as a person. My relatives are even failing to show their love to me. We don't seem to be people of one family. How do you expect me to lead a happy life with all these problems? And now I have developed ulcers which are also increasing to my problems (*a 23 years male PLWHA unmarried*).

This young man reported that he had found solace from the health workers and his church elder. This was also shared by most of the PLWHAs who expressed appreciation for the care and support that they had received from the clinic staff and home based care groupings.

The care and counselling support which I get when I come here at Lighthouse makes me believe that I am not dead but I can still live longer (*a 30 year old male PLWHA, separated*).

The experience shared in the above quote could be related to negative and challenging experiences that he had shared of verbal abuse from some family members, denied employment opportunity, unmet needs at family level and rejection from friends that might have led to having feelings of “social death” as indicated in the statement.

The key informants also narrated that they were seeing more of emotional problems in the patients that they had been meeting with.

Caring for people with HIV and AIDS we can say is an interesting job may be because you help someone to have a healthy life even though they have HIV; but at the same time you find that you meet problems that you need to solve for the patient, but you become like their relative since you have enlightened them to know their HIV status, they have faith in you. So apart from helping them to have health life, you also meet problems like what they meet at home (*a key info from Lighthouse*).

This indicates of the problems that PLWHAs encounter at home. This could mean that their problems make them transfer their relationship from their relatives to health care providers from whom they get respect despite their HIV status. The acceptance of the health care providers in away helped the PLWHAs to cope with their situation.

Most of the PLWHAs who were members of HIV and AIDS support groups narrated that they got encouragement from sharing their experiences with their friends who had similar problems. This was also shared by the PLWHAs at the time the researcher visited one of the support groups. The PLWHAs indicated that they were very much encouraged with the information that they share in the group therapies. Almost all indicated that they were appreciating the psychological support that they were receiving in the group therapies more than material support that they were getting like *likuni phala*. The PLWHAs share their negative experiences of living with HIV and home management of minor ailments and also tips on good nutrition and update each other on new information on HIV and AIDS.

Almost the participants indicated that they were also encouraged with the coming of the free ARVs. Previously many PLWHAs were not on ARVs because most of them could not afford paying for the medication every month. The free drug has changed the fatalistic view that people had on HIV and AIDS.

Some of the participants indicated that they had received encouragement from their church members though most of them did not disclose their status to the church members. The support and encouragement that the participants had received from the different sources helped them to cope with their status. This also gave them confidence that they were like anybody else who can contribute positively to the groups functioning. This made some PLWHAs come out publicly with their status and started serving their communities on HIV and AIDS related issues as role models.

## **8.2 Becoming a role model**

Some PLWHAs and key informants narrated of being involved in HIV and AIDS counselling and education. This followed their own experiences of suffering from an AIDS defining illness, experiences

of stigma and discrimination. The key informants who had reported of this involvement had participated in the initiation of the two support groups that the researcher visited during field work. Others were PLWHAs who participated in the radio diaries. These were both men and women who shared their life experiences of living with HIV and AIDS on six different radio stations in Malawi. Others once worked as United Nations Volunteers on HIV and AIDS. These volunteers were deployed to different organizations to create awareness on HIV and AIDS in different settings. The PLWHAs shared the view that they started this work because they had thought of teaching the public about HIV and AIDS from their own experiences with the illness. One of the radio diarists indicated that he joined the diarists program to save others from the pain that this condition brings to peoples' lives.

Some of the core participants indicated in their narration that they were encouraging others to go for testing. As indicated in the quote below;

Some of them it's because of the way they have been counselled and also the information which they get from us who have seen the benefits of coming here. We are able to tell them that knowing your status is not the end of everything but the beginning of new life. Drugs are available which will prolong your life. After convincing them some of them do come to access the care and support (*a 30 year male PLWHA separated.*).

This expression was common among all the PLWHAs who participated in this study. Though others did not disclose their status publicly, they encouraged sick members in the community whom they suspected that they could benefit from the Lighthouse services. A number of them reported that they were quite happy with the changes in health status of the people that they had encouraged to come to light house.

The key informant who was involved in the production of these radio diaries explained that involving the PLWHAs in sensitizing the public on HIV and AIDS seemed to be a powerful way of reducing stigma and discrimination. He indicated that this was shown by the feedback that the program received from the radio diary listener groups. The feedback indicated that other listeners had indicated that the diaries had encouraged people to start speaking openly about HIV and AIDS and other issues related to HIV disclosure. Others indicated that the diaries had helped to clear the misconceptions that they had on HIV and AIDS.

Though participants indicated of the influence that they had made on others to go for HIV testing this was not without a cost. One of the PLWHAs who had once worked as a volunteer in one of the Government Ministries indicated of the experiences that she had gone through;

The other thing which I forgot is that when I went on the GIPA<sup>18</sup> program I was placed at (...) ADD<sup>19</sup>. So before I reported at the ADD, people were told in advance the person who is coming to assist with HIV and AIDS program is HIV positive, so the only person whom I was able to interact with was my immediate boss. The rest of the staff made sure that they kept away from me. I was given my own office, away from others for confidentiality so that people should be free to come to my office and discuss issues concerning HIV and AIDS. Instead people were shunning away when they saw that my office was open. I spent almost three months and decided to meet management. I explained to them why I was there and the attitude of people that they are not interested to come to my office. Even if they have gone for lunch they were making sure that they sat away from me. And among the cleaners there was only one who was free to chat with me. I tried to put up posters for HIV and AIDS on the notes board and the next day I could discover that everything has been removed. Later there was a new Manager who called for a meeting and when I talked about my experience with HIV people started coming to my office. The first group which I addressed was the Lilongwe district assembly and when I talked to that group everybody was happy and eventually they all changed their attitude and started chatting with me. Eventually at the (...) ADD when I wanted to address the members of Staff and when I approach a messenger to notify them about the meeting others were saying they cant waste their time to attend to such meetings. Let only who have HIV and AIDS die. I knew that the reason could be that they were deliberately being sarcastic. They could be making such remarks but they don't know their status because they had never gone for a test (*a 42 year female PLWHA a, widow and a mother of 2*).

A male key informant who participated in the opening of NAPHAM<sup>20</sup> also shared similar experience at the time NAPHAM was just opened that was 1993. He had narrated that it took sometime for people to open up and join the group. They had to organize a number of meetings sensitizing the people about the association and its aims. Later, people came in to join the association. At the time when the researcher visited he indicated that the group had over 400 members. Most of them are actively participating in home based care program and community sensitization. However, there are others who had just opened up in the support groups and not in their communities. These only participate in group therapies.

When the researcher asked what had helped them to cope with these challenges. The key informant from NAPHAM indicated that he was encouraged with what he had heard about the success of Uganda

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<sup>18</sup> GIPA – greater involvement of people living with HIV and AIDS

<sup>19</sup> ADD- Agriculture development division

<sup>20</sup> NAPHAM-National Association of People living with HIV and AIDS in Malawi

in the fight against the epidemic. He explained that Uganda used PLWHAs to teach the community about the dangers of the infection.

Because of this beginning there is greater involvement of people living with HIV and AIDS in Malawi in programs such as the ones stated above. This has been reinforced by the Malawi AIDS policy document.

Goffman (1963) claimed that following a lengthy period of learning to conceal one's stigmatizing attribute, comes a time when the stigmatized individual accepts himself and his failing and may voluntarily disclose of it(88). This is most often done through some guidance from professionals. As indicated in the radio diarists who tell their life stories of living with HIV and how they are managing to handle life challenges just like any member of their society can do. The focus most often of the public disclosure is on medical aspects of the "mark" not on the moral aspect of it. This is how the stigmatized manages to reinstitute themselves into the community.



## **Concluding remarks**

The main objective of the study was to explore the experiences of people living with HIV and AIDS with the main focus narrowed down to stigma. In summary, the findings of this study have indicated that stigma in Lilongwe, an urban setting in Malawi is a social construct that is influenced by a number of socio-cultural factors. These include; religion, traditional beliefs, scientific knowledge and social structures such as gender. The interplay of these factors has contributed to the people's negative reaction towards receiving HIV/AIDS diagnosis. It has also created negative attitude in the general public towards HIV and AIDS as indicated by the gruesome experiences of PLWHAs at different societal levels. Among other challenges include; reduced employment and other life opportunities.

There is a possibility that some of the people who stigmatize others do so without the knowledge that their actions are stigmatizing because of the way how stigma is defined in the Malawian urban setting.

The findings have also indicated that HIV and AIDS related stigma is not static but changes with disease progression. Though, the findings indicated of some challenges in the experiences of the PLWHAs that are scary, other PLWHAs managed to come out into the open to give a human face to the epidemic in the fight against stigma.

## **Recommendation**

### **Stigma reduction**

There is need to teach the public on the definition of stigma and emphasize on issues such as the terms that people use for the infected and the infection itself that they are stigmatizing to the infected individuals. These teaching should also emphasize on HIV transmission since findings have indicated overwhelming fear of HIV being transmitted through casual contact. If possible the teachings should be organized in away that focus on generalizing HIV infection as any other

infections since it is not everyone that has the infection that was engaged in promiscuous behaviours.

There is an urgent need to involve Traditional leaders and religious leaders at all levels in the fight against the epidemic and stigma. Since these people have an influence that can bring a positive change in the attitudes of the people they serve in their communities. Through their involvement communities should be encouraged to discuss openly around sexuality, HIV and gender related issues by building positive norms through community involvement in discussions about these issues and creating environments where such issues can be discussed without violating the society's norms.

There is also need to provide counselling and support to families of people living with HIV and AIDS.

#### **Anti-discriminatory measures**

There is need to educate managers, employers and employees at all sectors to promote. There is also need to mobilize private sectors to develop and implement non-discriminatory employment and work policies. Those that have the policies should be encouraged to implement what is stipulated in their policies and create awareness to employees of the policies put in place. In health institutions, health personnel should receive adequate training and be updated on HIV/AIDS related issues.

If possible PLWHAs should have access to small loans (micro-credit scheme) in the support groups to help them have access to basic needs in life since some of those that lost their jobs had problems to get loans from other organizations.

Involvement of PLWHAs should be encouraged at all levels to demystify the misconceptions that people have on HIV/AIDS. This might as well help others to position themselves in situations and appreciate the suffering and injustice that other PLWHAs have gone through.

**Protection from discrimination**

Government should put in place laws that protect PLWHAs rights. Also create awareness among PLWHAs of their rights.

**Future research**

- It is important that the socio-cultural factors be explored at a wider scale to gain an in-depth understanding that can help to come up with solutions to reduce stigma since findings of this study can not be generalized to the whole population.
- There is need to explore the role of religious institutions in the fight against HIV and AIDS epidemic.
- There is also need to explore the reasons for the un-equal imputation of blame between men and women in regard to HIV infection.
- There is need to assess the impact of the anti-stigma programs that are put in place such as the greater involvement of PLWHAs and other home based care programs.

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## APPENDICES

### Appendix 1: Participants demographic information

Participant name.....

Age.....

Sex.....

Tribe.....

Religion.....

Marital status.....

Length of time in marriage.....

Occupation.....

Level of education.....

Location (urban, semi-urban, urban).....

Number of children .....

Date tested for HIV.....

Interview number.....

Home district.....

## Appendix 2A: Interview guide for core participants

Interview no.....

date.....

Time started.....

Time finished.....

Introduction; welcome participant

Introduction of the researcher

Explain the purpose of the interview and discuss issues of confidentiality

Thank participant for deciding to take part in the study

1. Would you please tell me how your life has been like since you were diagnosed having HIV/AIDS?

Probe for:

immediate reaction to the new diagnosis (emotionally and physically)

Issues of disclosure (did they disclose? to whom? If not, why?)

If not, how are they managing to conceal the information? Any

negative or positive effects

if disclosed what made them do so

how did they do it?

2. Would you mind telling me how your life was like before you tested for HIV?

Probe for:

Uncertainties about their risk of contracting HIV before health problems appeared?

If any did they interfere with their social life?

If any what were the strategies that were taken to manage the uncertainties?

3. Would you explain to me what having HIV/AIDS means to you?

Probe for: what do others say or think of what having HIV/AIDS is?

Family members,  
friends  
community

4. Have you experienced any social interaction changes with your disease progression?

If yes, would you mind share the experiences with me?

Probe for: before onset of symptoms

during the time that symptoms started showing  
how did they manage to cope with it?

5. How have the following been of assistance to you?

Family members, employer, HIV/AIDS support group  
friends, church, community and health facility

6. Are there any positive events that have helped sustaining your life since the time you

were diagnosed with HIV/AIDS? If yes ask if she can share the events

7. Do you know of other PLWHA who are not able to access health care, social and spiritual

care? If yes, probe for situations that are hindering them access

for those accessing the services find out against which obstacles and in response to which triggers.

## **Appendix 2B: Interview guide for key participants**

In-depth interview guide for key participants

Interview no.....

date.....

Time started.....

Time finished.....

Introduction of the researcher

Explain the purpose of the interview and discuss issues of confidentiality

Thank participant for deciding to take part in the study

1. Through your encounter with the PLWHA, would you mind sharing with me

what you think about their experiences of living with HIV/AIDS?

Probe for these stages; time before HIV/AIDS testing

Soon after HIV/AIDS testing

Time when symptoms begin to show

Time when full symptoms of HIV/AIDS manifest

2. What impact does the services that are rendered here, have on lives of PLWHA

3. Are you satisfied with these services? If no, would you mind sharing the reasons why?

4. Would you explain to me what HIV/AIDS means to you?

Probe on: what others people think about HIV/AIDS (myths and beliefs that other people have towards HIV/AIDS).

5. Studies from other places have shown that PLWHA face negative reactions from their families, friends and the communities they live in. Does this happen to some of the PLWHA that you meet with here or you know? If yes,

Probe for; how does this happen?

reasons why people do this?

how do the PLWHA react to it?

6. If we are to compare these reactions now and the first time when HIV/AIDS was first identified here in Malawi, are there any changes? If yes

Probe for: type of changes and if it has any effects on the PLWHA.

If no, find out reasons why

## Appendix 3: Approval letter from the ethical clearance committee

Telephone: + 265 789 400

Facsimile: + 265 789 431

All Communications should be addressed to:  
The Secretary for Health and Population



*In reply please quote No. MED/4/36c*

MINISTRY OF HEALTH AND POPULATION

P.O. BOX 30377  
LILONGWE 3  
MALAWI

7<sup>th</sup> July, 2005

Mrs. S. Mwale  
Dept of General Practice and Community Medicine  
University of Oslo  
P.O. Box 1130  
Blindern  
Norway

Dear Madam

**Re: Protocol # 347: The experiences of people living with HIV/AIDS receiving health care services at Lighthouse, clinic, Lilongwe**

I am pleased to inform you that the National Health Sciences Research Committee has approved the above study after considering that all concerns that were raised during the review meeting held on 24<sup>th</sup> June, 2005 have been addressed adequately.

As you proceed with implementation of your study please ensure that all requirements of the National Health Research Committee are followed.

Yours faithfully

A handwritten signature in black ink, appearing to read 'W M Kazembe'.

W M Kazembe

For:

**SECRETARY FOR HEALTH**



## **Appendix 4: CONSENT FORM FOR PARTICIPATION IN THE STUDY**

You are being invited to join in a study. The purpose of this study is to explore the experiences of people living with HIV/AIDS.

This information will help in the planning of programs that meet the needs of the people living with HIV/AIDS.

The study will have two phases of interviews. One interview will be conducted now. After two-three months we will have a follow up interview on issues discussed in the first meeting and to find out if there are some new experiences that might have occurred between now and that time. The interviews might take approximately 1 hour to 1 hour 30 minutes.

If you decide to participate in this study you will be asked questions pertaining to your experience of living with the Virus. With your permission interviews will be recorded on a tape recorder and notes will be taken as it is not possible to remember everything we are going to discuss at the end of the interviews. All the information given will be kept confidential, only those who are involved in this study will have access to your information.

All personal identification information will be kept separate from the recorded interviews and the interview notes. The recorded interviews will not include your personal details.

Your participation in this study is voluntary. You are free to refuse to join or withdraw your participation at anytime. This will not affect your relationship with doctors/ nurses at this clinic, neither will it affect the care you receive at this clinic. There is no direct benefit to you for participating in the study, the information you will give will help to come up with programs that will help PLWHA in future. You will receive 250MK for your transport in the second interview.

All the recorded information will be transcribed and compiled and submitted to the University of Oslo as part of my exam. Other copies will be submitted to the Ministry of health and Light House Clinic. These reports will not include personal identification details. At the end of everything all tapes containing the recorded information and notes taken during the interviews will be destroyed.

This study has been ethically approved by the committee that looks into the rights of Human subjects participating in research studies, the Malawi National Health Sciences Research Committee. If you have questions regarding your right as a subject in this study you can contact the chairman of the committee on this number.....

If you have questions you can contact the researcher on this phone number (+2659955600) or write to her on this address. C/o UNC Project, private bag a-104, Lilongwe. This study has been sponsored by NORAD in Norway.

I understand the purpose of the study and therefore have accepted to participate.

.....	.....
Participant signature	date

.....	.....
Researcher's signature	

**Appendix 5: AGREEMENT FORM FOR RESEARCH ASSISTANTS**

I..... Pledge that I understand the purpose of this study and that I will never ever use the information gathered through this study for my own interests or breach the confidentiality of any of the participants who will take part in this study at any time without the knowledge of the Principal Investigator.

.....  
Signature of research assistant

.....  
date

.....  
Signature of witness

.....  
date

.....  
Signature of the Investigator

.....  
date

## **Appendix 6: HIV positive counselling guide line**

### **Preparing for the Counselling Session**

To promote confidence and openness in the person being tested, use a private room for counseling away from all other clinic activities. Put a “*Do Not Disturb*” sign outside the door to make sure that there are no interruptions from colleagues or other clients. Have comfortable chairs. Sit side by side with the client facing you ( angular position ) or Sit opposite each other (do not sit behind a desk). Put the phone off the hook to avoid interruptions during the counseling session. Have everything you may need for the session (e.g. pen, paper, participant folder) ready before you begin.

#### **1. Greet the Client and Ask How She Has Been Since You Last Saw Her**

- “I am glad you have decided to come for the results of your HIV test. It is important to know your HIV status to protect yourself and others from HIV infection. Did you bring someone with you (partner, husband, or friend) whom you want to be here when I give you the results? Do you have any questions?”

#### **2. Give the Test Results**

Most clients will want to hear their results as soon as possible. When the client is ready, give the test results in a neutral tone of voice:

- “The results of your blood test have come back from the laboratory. Your blood was found to be HIV positive; that means that you are infected with HIV.” *Wait for her to respond before proceeding.*

#### **3. Assess Cognitive Understanding, Check for Misperceptions and Misinformation**

Find out how much the client knows about HIV/AIDS and what the test results mean to her.

- “Please tell me what this positive result means”. Explain further if client still does not understand well.
- “The test results shows HIV infection, not AIDS. It also does not show how long you have been infected. Being positive does not mean that you have AIDS. It is possible to be HIV positive and live a healthy life for a long period of time before developing AIDS. One of the advantages of knowing that you have the HIV virus is that symptoms of HIV-related illnesses can be identified early and treated promptly. It is important to visit the clinic or your doctor each time you do not feel well.”

#### **4. Assess Emotional Understanding**

- “Please tell me how you are feeling right now?”  
(If necessary, probe: “some people may feel shocked or numb. Other people may feel angry or frightened. How are you feeling?”)
- “Is there anyone you will be able to tell that you are HIV positive (*could be partner, relative or friend*)? How are you going to tell them? (*Role play this with client*). What are your concerns about telling them? Does anyone know you came here for your test results?”

#### **5. Partner Testing and Notification**

- “You can transmit HIV to your sex partners. Do you have a husband, boyfriend, or a regular sex partner? Do you know if he is infected with HIV? If he does not know if he has HIV, your partner is welcome to come here for voluntary counseling and HIV testing.”
- “I would like to encourage you to inform your partner(s)/husband about your test results. I know that this may not be an easy task for you. Do you have any fears about telling him? Are you concerned that he might be angry when you tell him? Would you like me to be there when you tell him?” *Have woman come up with a script that she would use to talk to her husband/partner but assist with phrasing/wording if she needs help.*

## 6. Discuss Active Measures for Staying Healthy

- “It is important to take care of yourself. There are many things you can do to help your body stay healthy, and they are all things you can do for yourself.”

### *Eat healthy:*

- “First, to keep yourself healthy, you should eat nutritious foods (find out from the client available foods in her home). Vitamin and mineral supplements (such as Vitamin B complex, C, E, and zinc) may be useful.

### *Avoiding infections:*

- “Second, it is important for you to try to avoid infections. Avoid new STDs and seek treatment early for any infections you may have. Your body may have difficulty fighting them.
- Maintain good hygiene, such as washing your hands and brushing your teeth. This will reduce the chance of getting an infection.
- Avoid smoking, heavy drinking, and drugs. Smoking is particularly dangerous because it may cause lung infections that are common with HIV. Alcohol and some other drugs like **Mbanje** suppress the immune system, may lead to depression, and lead to risky sexual behavior by lowering inhibitions.”

### *Caring for your body:*

- “Third, take care of your body with both exercise and rest.”
- “Exercise regularly, like walking or cycling. It is important to keep fit as it will make you feel well.”
- “Sleep and rest enough and avoid being over-tired. Try going to bed earlier than before. You may need to adjust to a lower level of activity especially when you are ill. It is important for you to relax and reduce stress. Talk to a counselor, a friend or relative instead of bottling up worries inside.”
- “Find people who accept you and care about you, and spend time with them. Having support from others can help you think positively and stay active. Spend time with your friends and relatives who make you feel good and do not upset you. There are various support organizations (*name them*) for people like yourself living with HIV, in Harare/Chitungwiza. You may want to consider joining one of these support groups. You may feel relieved when you talk to other people who are in a similar position as you. (*Give the client a copy of the Referral List*). Would you like me to refer you to any of these organizations/support groups?”

## 7. Review Routes of Transmission

- “Now, I would like to talk about how people get HIV, so you can understand the virus and so you know how to keep from giving it to others. HIV is transmitted from person to person, in three ways: through blood; from mother to child during pregnancy, birth, or breastfeeding; and through sex.”

### *Blood:*

- “Let’s start with blood. You could infect others by donating blood or by sharing sharp instruments such as needles, razor blades and knives, because they carry blood. You should not let others use knives, needles, or razor blades that have your blood on them. Also, you should not donate blood.”

### *Mother to child:*

- “Second, HIV can be transmitted from HIV infected mothers to their new babies. If you get pregnant, you can pass the HIV virus on to your child during pregnancy, at birth or during breastfeeding. Are you interested in getting pregnant in the near future, or does your husband/partner want you to get pregnant?”

### *If yes...*

- “You know the 3 different ways through which you can pass the HIV virus on to your child if you get pregnant? If both you and your child get sick, who is going to look after you?”
- “Who would look after your children if you and your husband could no longer take care of them?”
- *Discuss contraception:* “If you decide that it may be better not to become pregnant, you may want to consider using a hormonal method of contraception in addition to using condoms. Hormonal methods of contraception include the pill, injectables, and Norplant. Are you interested in these methods?” (*If yes, refer to Spilhaus Family Planning Clinic*).
- *Discuss breast-feeding:* “Are you currently breast-feeding a child?”

### *If yes...*

- “You may pass the HIV virus on to your child through your breast milk. The only way to be really safe once you have HIV is to not breast-feed your child at all, but to feed it infant formula instead. Infant formulas are expensive to buy, and you may not be able to afford the cost. There may, however, be other ways to reduce the risk of giving HIV to your child, such as feeding your child goat’s milk. You also may start your child on solid food as early as possible.

### *Sex:*

- “The third way in which HIV can be transmitted to others is through sex. HIV is found in semen, vaginal secretions, and blood, and you could expose your partner(s) to your vaginal secretions (semen if male) or blood by having unprotected sex with them. Do you know what “unprotected sex” is? *Clarify any misunderstanding and, debunk myths.*

During the next session we will give you information on how to prevent transmitting HIV to others during sex. (*Go on to Condom Promotion script*)